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# National Strategy for COPD and End of Life Care

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# The End of Life Care Strategy

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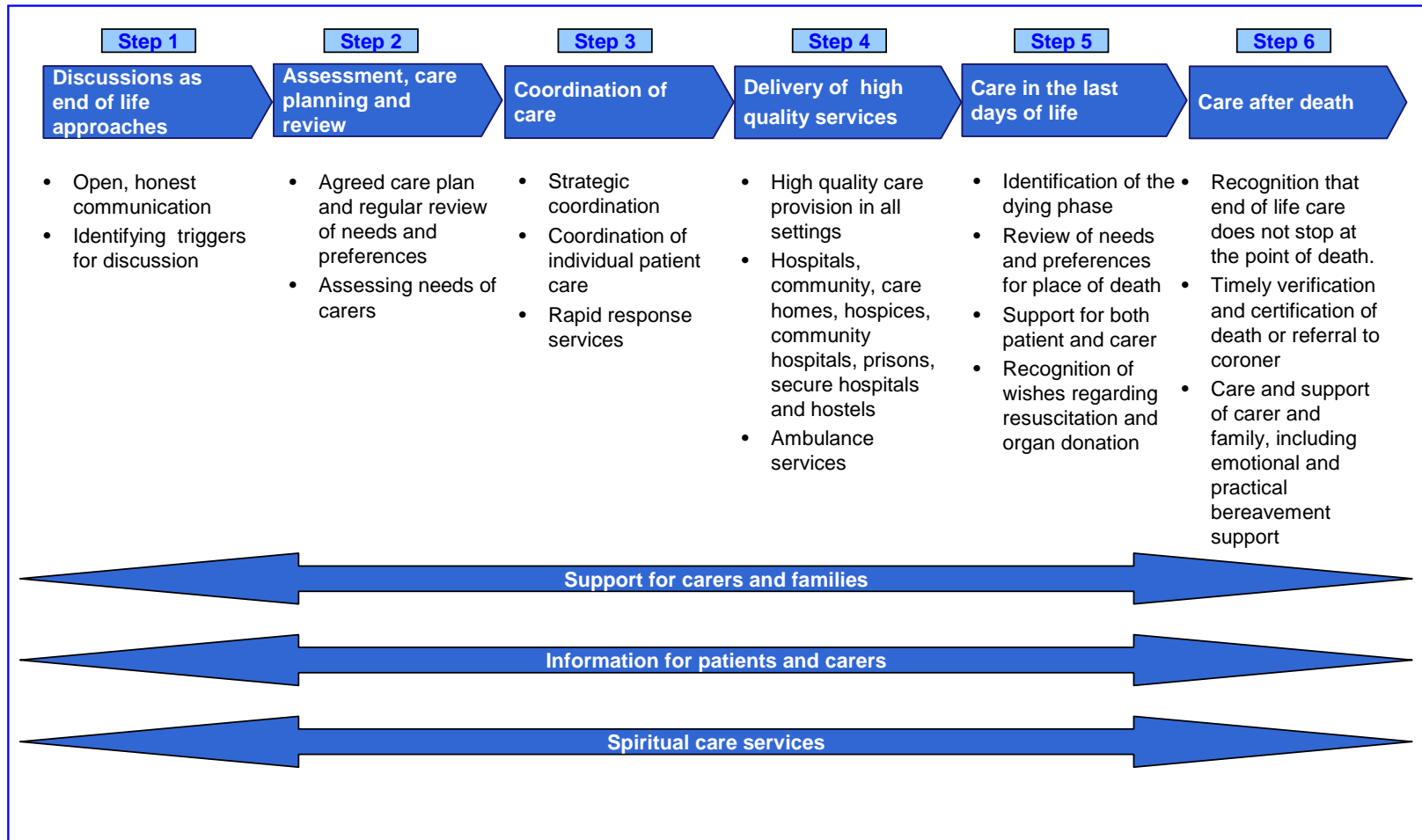
- Around 500,000 people die in England each year. This will rise to around 530,000 by 2030
- DH has never had a comprehensive strategy on end of life care
- Some patients receive excellent care, others do not
  - 54% of complaints in acute hospitals relate to care of the dying/bereavement care (Healthcare Commission 2007)
- Hospices have set a gold standard for care, but only deal with a minority of all patients at the end of their lives

# The End of Life Care Strategy: Scope

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- The Strategy
  - Covers all conditions
  - Covers all care settings (e.g. home, hospital, hospice, care home, community hospital, prison etc.)
  - Has been developed within the current legal framework

# The End of Life Care Pathway



# The End of Life Care Pathway

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1. Identifying people approaching the end of life and initiating discussions
  - Major culture change needed amongst clinicians
  - Difficulties in prognostication are recognised
  - Communication skills training required
2. Assessment, care planning (and review)
  - Need for training recognised
3. Coordination
  - Easy to talk about; difficult to deliver
  - Coordination is needed within teams (e.g. GSF) and across organisational boundaries (e.g. coordination centres)

# The End of Life Care Pathway

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4. Delivery of high quality services

5. Care in the last days of life

- Liverpool Care Pathway strongly recommended

6. Care after death

- The Liverpool Care Pathway has modules for care after death, which can also be used for sudden deaths

# Care in different settings

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- Community
  - Importance of 24/7 rapid response community nursing services for end of life emphasised
  - GSF or equivalent recommended for use in general practice
- Hospitals
  - 58% of deaths occur in hospitals
  - Hospitals will continue to have a vital role in caring for the dying
  - A major culture change is needed – both amongst clinicians and NHS managers: Death should not be perceived as a failure
- Care homes
  - Major scope for improvement of end of life care in care homes.
  - The NHS End of Life Care Programme (2004-2007) has shown what can be achieved, using GSF, LCP, PPC etc.

# Care in different settings

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- Hospices
  - Provide beacons of excellence in the provision of end of life care
  - Should be encouraged to consider what roles they would wish to deliver within an integrated local service
    - e.g. Awareness raising
    - Education and research
    - Coordination
    - Specialist outreach services (e.g. to care homes or community hospitals and for patients with conditions other than cancer)
  - Any new services should be appropriately funded by PCTs

# Support for Carers and Families

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- Carers provide invaluable support for people approaching the end of life, but may need support themselves
- Carers are central to the team and should be considered as ‘co-workers’
- Carers should be offered an assessment of their own needs and to have their own care plan which is reviewed regularly
- Bereavement care should include support for those bereaved through sudden death and also the needs of children

# Spiritual care services

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- Recognition of the spiritual dimension of each person
  - Each person is unique and should be treated with dignity and respect
  - People approaching the end of life need to discover their own way of making sense out of what is happening and helped to express this
- Action
  - Spiritual needs should be assessed as part of all patient and carer assessments
  - Ritual actions are often helpful for patients and carers as are occasions of remembrance for the bereaved
  - The role of chaplains should be fully integrated into the multidisciplinary team

# Workforce Development

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- **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**
- **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**

# Measurement and Research

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- Measurement
  - We need to be able to assess whether individual organisations are providing high quality care and whether progress is being made across the country as a whole following publication of this strategy
  - Currently available measures (e.g. place of death) are useful, but do not provide information on quality of care or on where patients might have chosen to die
  - Better use could be made of existing data sources (e.g. by combining ONS and HES data)
  - The difficulties related to measurement of end of life care need to be recognised
  - Measures of structure, process and outcomes are all useful

# Measurement and Research

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- Quality standards to assess the structure and process of end of life care are currently being developed, in association with SHA End of Life Care Clinical Chairs
- Outcome measures
  - Place of death
  - Professional audits (e.g. LCP: National care of the dying audit – hospitals and GSF After Death Analysis)
  - Surveys of bereaved relatives (VOICES)
- Establishment of National End of Life Care Intelligence Network – bringing together ‘owners’ of data and those with interest / expertise in this area

# Making Change Happen

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- Funding
  - Manifesto commitment to double expenditure on palliative care
  - Baseline:
    - NHS expenditure on specialist palliative care (2000) = £130m
    - Central budget for specialist palliative care (2003/4) = £50m
    - Total = £180m
  - Commitments in End of Life Care Strategy
    - 2009/10: £88m
    - 2010/11: £198m
  - Most of this funding will be put into PCT baseline budgets, but they will be expected to monitor investment. Can be used for any of the areas identified in this strategy
  - Some funding for SHAs (workforce development)
  - Small central budget for national initiatives

# Making Change Happen

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- Local strategic planning
  - All PCTs will be expected to develop strategic plans for end of life care, building on their baseline reviews and taking account of the national strategy and their SHA vision
  - This is in line with the Next Stage Review commitments for PCTs to set out plans based on each of the 8 clinical pathways
  - Essential that PCTs engage all relevant providers, including the voluntary sector, in this. They may wish to establish a Partnership Board or a Network

# Making Change Happen

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- Provider organisations
  - Each provider organisation involved in end of life care should develop a plan which is congruent with local and national strategy
  - The draft quality standards may help providers to identify areas which need action

# Making Change Happen

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- National support
  - National coalition on end of life care
    - To provide public awareness and to change attitudes
  - National End of Life Care Programme will continue to help spread good practice
  - Survey programme of bereaved relatives to be established
  - National End of Life Care Intelligence Network to be established
  - Research initiatives will be supported
  - Professor Mike Richards will continue to provide leadership within DH. He will report annually on progress to Ministers
  - An external stakeholder group will be established to advise on this

# National Strategy for COPD

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- Outline a vision for COPD services in England
- Will make recommendations across all areas of the disease pathway to help guide the development of local services from prevention through to end of life care
- Process considers how to implement and monitor the standards

Modern Standards and Service Models

Modern Standards and Service Models

### Coronary Heart Disease

national service frameworks

### Diabetes

national service framework

### *The National Service Framework for Renal Services*

Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care

Executive Summary

National Service Framework for Diabetes: Standards

2005

February 2005

2000

2001

### National **STROKE** Strategy

### Putting prevention first

Vascular Checks: risk assessment and management

2007

2008

# Scale of COPD

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- Within the population of England of 55 million it is suggested that up to **4 million people have COPD**, but only **0.6 million people are diagnosed** (DH, 2007)
- One in eight hospital admissions are for COPD which equates to 1000 admissions and 25,000 GP consultations per year in a typical PCT
- In 2000, the WHO estimated 2.74 million deaths worldwide from COPD
- 14% of all deaths in the UK are due to lung disease
- In the UK, COPD is the cause of death in 6.4% of men and 3.9% of women

# What the strategy will include

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- Raising awareness
- Focus on prevention and risk reduction
- Early identification, confirmatory diagnosis and severity assessment (ongoing)
- Clear care pathways and models of care provision for acute (aggressive management of acute exacerbations) & chronic care- Wagner's chronic care model
- Structured support and action planning
- Recognition of the importance of both pharmacological and non pharmacological interventions
- Smoking cessation
- Equity of access to pulmonary rehabilitation and supportive care
- **Access to specialist services at end of life**

## Sub-group looking at Palliative and EoLC

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Included:

Dr Mike Morgan – Consultant and President elect of BTS

Dr Noel O’Kelly – GP

Prof Sam Ahmedzai, Elaine Dean, Andrew Dickman,

Jane Scullion, Dr Patrick White

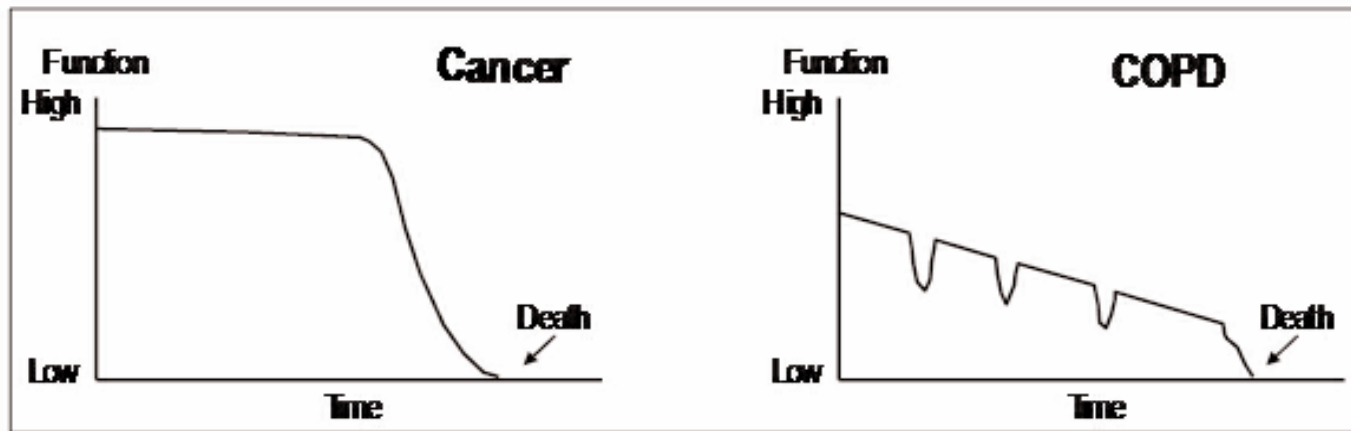
Plus input from NCPC, people with advanced COPD, carers

## Palliative and EoLC in COPD – feedback from stakeholder engagement

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- People with COPD experience at least the same but often more severe symptoms than people with other conditions – they have multiple, extensive and prolonged need
- Struggled to define when the end of life stage was reached in COPD
- Lack of access to palliative and end of life care services
- Little or no support or follow up following bereavement

## Comparisons of patterns of physical decline



In contrast to cancer where the terminal phase is relatively clearly defined, COPD illustrates gradual decline over a number of years is punctuated by acute, often severe exacerbations, any one of which may, or may not, prove fatal.

*Courtesy of RAND Corp USA*

# National Strategy for COPD and End of Life Care

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Questions posed by the sub-group looking at Palliative and EoLC were:

- **What definitions are there for 'end of life' for COPD patients, including: time period; stage of disease; defined by consensus (patient, carer, clinician); acknowledged patient right to exercise choice?**
- **Are there markers for considering end of life / survival in a patient with COPD, that would trigger end of life care services including: physiological; functional; health status; exacerbation frequency; co-morbidities; psychological; recognised scoring tools?**
- **What health and social care interventions/services are effective for managing end of life care in a patient with COPD (symptoms; quality of life; patient, carer and family satisfaction; place of death)?**
- **What intervention health and social care services are effective for supporting carers and families through end of life care and the bereavement process?**
- **What evidence exists of equality of access to supportive care for COPD patients at end of life?**

# Conclusions from evidence review

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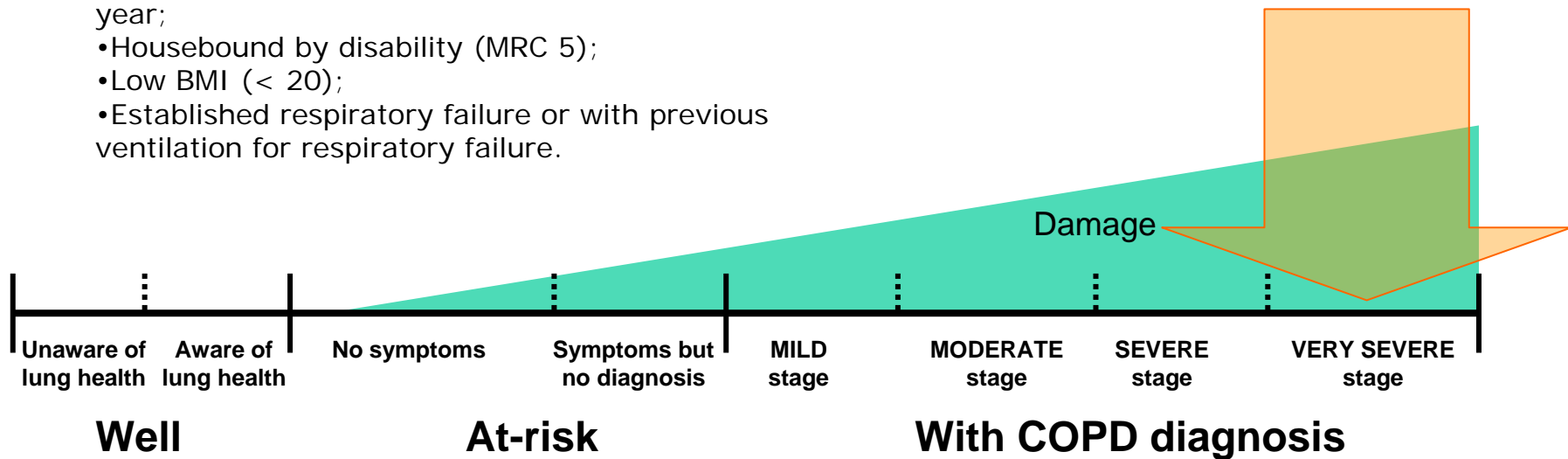
- Compared to the amount of evidence available to other subgroups, the volume of research into EoL care overall is small, especially COPD-specific studies
- The greatest volume of evidence has been found for the questions on markers and interventions. Less has been located on definitions, supporting carers and equity of access to care.

# Recommendations on End of Life Care

Defined as:

- Very severe airflow obstruction (FEV1 < 30 % predicted);
- History of two or more severe exacerbations requiring a hospital admission in the preceding year;
- Housebound by disability (MRC 5);
- Low BMI (< 20);
- Established respiratory failure or with previous ventilation for respiratory failure.

- Access to supportive care for patient and family through to bereavement stage
- Managed according to guidelines, e.g. Liverpool Care Pathway



# Implementing the Strategy

## Support

- Care Services Improvement Partnership
- National Support Teams

## Lead Strategic Health Authority

Contact in Each StHA

## Payments

- Quality and Outcomes Framework (QOF)
- Payment by Results
- Practice Based Commissioning

Taken forward locally by Managed Clinical Network

## Commissioning

- Guidance/toolkit
- World Class Commissioning
- Local needs assessments
- Strategic commissioning

## Monitoring Progress

- Metrics

## Supporting the Individual

- Self-care
- Choice
- Information

# What next (1)

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- Communication guide with NCPC?
  - Introducing the concept of and need for end of life care
  - EOLC needs assessment
  - How care will be co-ordinated/delivered
  - Advance care planning
  - Place of care
  - Available services
  - Support for carers
  - Bereavement support for carers
  
- Workforce requirements for palliative and end of life care
  
- Examples of good practice
  
- Working with <http://www.endoflifecareforadults.nhs.uk>

## What next (2)

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- Development of care plans with regular review – every 3 months for advanced COPD
- Development of respiratory networks – they will need to include include palliative and EoLC in the pathway
- Guide on management of medicines – this will have section on advanced COPD and End of Life Care. Will cover:
  - Specific treatment aims
  - Specific medicines
  - Shared decision making
  - Devices and monitoring
  - Professional roles

# Communication with healthcare professionals

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- Working with GPIAG and BTS to develop a DVD called 'Living and Dying with COPD'
- Formal launch is at the BTS Winter Conference in December
- Free education package to help develop communication skills for practitioners

## Percentage of units with formal arrangements to receive Palliative Care 2008 (2008 National COPD Audit – RCP/BTS/Health Foundation/BLF)

SHA Region	Units with palliative care arrangements	% with palliative care arrangements
East Midlands	6/9	67%
East of England	10/17	59%
London	18/31	58%
North East	5/13	38%
North West	16/27	59%
South Central	7/12	58%
South East Coast	9/17	53%
South West	8/18	44%
West Midlands	8/20	40%
Yorkshire and the Humber	10/21	48%
England	97/185	52%

# Research/Pilots

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- What are the most effective treatment regimes for people in the end of life phase of COPD?
- What are the needs of people with COPD and their carers at the end of life stage and how can these be best delivered?
- Any others?

# Conclusion

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- We don't do death well in COPD – this needs to change
- If we can identify people needing palliative and EoLC we can help them plan for place of death, with minimum spiritual, psychological and physical distress
- With appropriate support for family and carers