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Palliative care for Non-Cancer

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# Background

- In 2005 **cancer** was responsible for a relatively small percentage of deaths worldwide **(13%)**
- Long term conditions caused 47% (*WHO 2008,2005*)
- **By 2030, ↑ from 58 million to 74 million  
-organ failure,-physical and cognitive frailty  
(Mathers 2006)**
- Palliative care services typically still cater only for people with cancer (*WHO 2004*)
- Dying of the "wrong" condition (*Murray et al, 2005*)

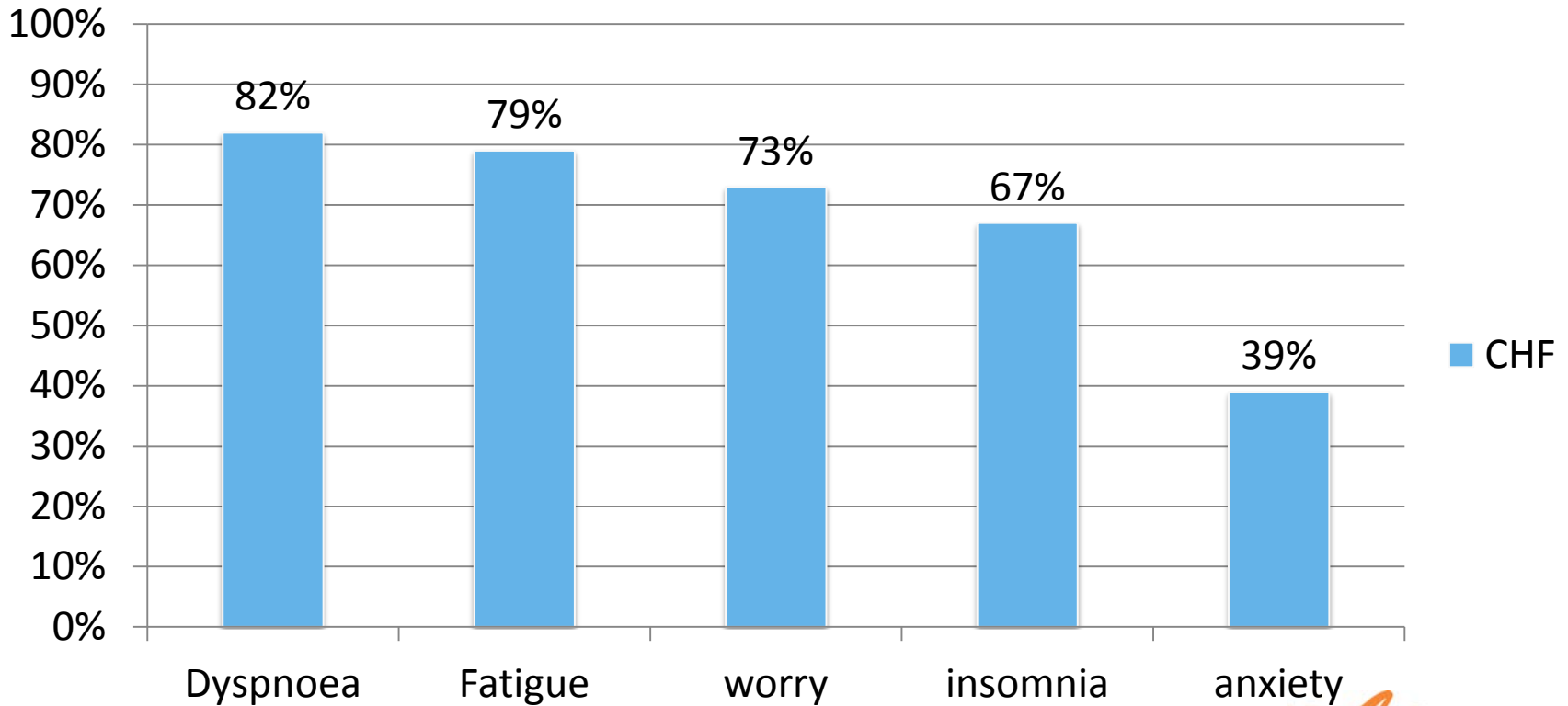
- 2/3 of people dying are aged > 75yrs.
- 2012- Leading cause of death
- Male : Heart Disease (15.6%)
- Female : Dementia (11.5%)

# Background- Heart Failure

- 900,000 people in UK , 68,000 new cases / year
- To rise by 50% over the next 25 years
- 5% admissions, 50% readmissions in 1 yr

# Symptom burden

CHF



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# Prognosis

- 40% mortality within first year.
- Worse prognosis than many cancers.
- 10-15% of people aged > 80
- Despite treatment – prognosis poor, condition irreversible, incurable.
- Only 6% referred to palliative care.

# Gadoud 2014

- Fewer Heart failure referred/ recognised as Palliative compared to cancer.
- 3122 DIED- 234 on Palliative care register **(7%)**
- 69/234 **(29%)** – entered in the last week.
- Gadoud et al 2014. Palliative care among heart failure patients in primary care: A comparison to patients with cancer using English family practice data. PLoS ONE 2014;9:e113188.

Non-Cancer patients also

**Have High  
symptom burden**

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# Ref.

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Why do we  
think it's the  
case?

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# Challenges

- The difficulties of recognising dying
- Dealing with uncertainty and prognostic paralysis
- Where and when does palliative care interface?
- Specialist vs. Generalist debate

**Kendall et al 2015**

**Dancing to a different tune: Living and Dying with  
Cancer, Organ failure and Physical Frailty.  
10.1136/bmjspcare-2014-000838.2.**

**Cancer based end-of-life  
care poorly suited to the  
needs of those dying in  
other ways.**

BMJ Supportive & Palliative Care March 2015 ;5(1):101.

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# 828 interviews

- Cancer- Clear beginning, middle and anticipated end.
- Non cancer:
  - Unclear beginning
  - Further unclear middle...
  - Many ... Not had a clue about the END.

# Trajectory: long term limitations with intermittent serious episodes

**End-organ failure**      *(Murray et al, 2005)*

- Heart failure, COPD.
- Usually ill for many months or years
- acute, often severe, exacerbations.
- Deteriorations are generally associated with admission to hospital
- Each exacerbation maybe life-threatening

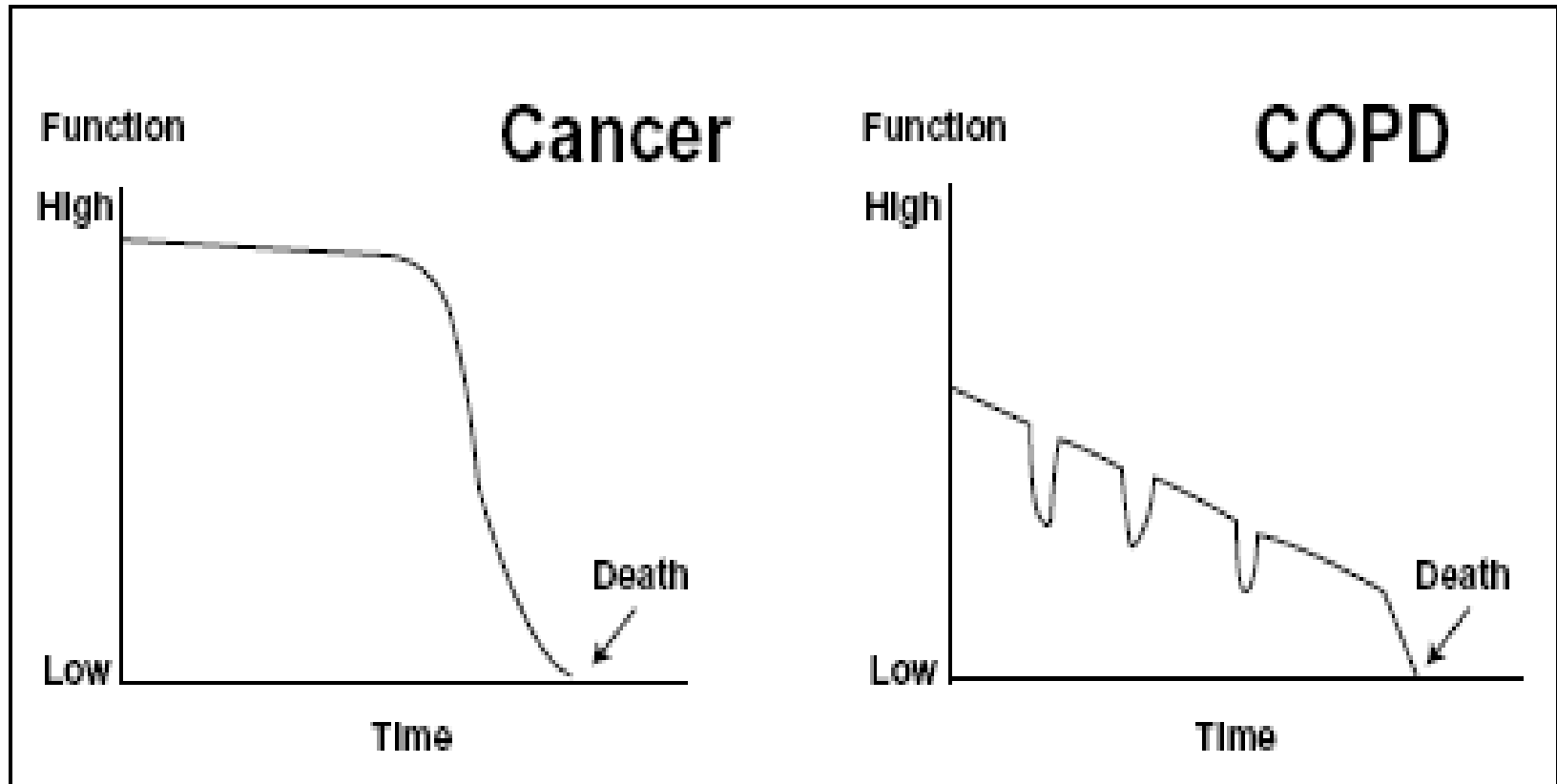
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- If survives such episodes, a gradual deterioration in health and functional status is typical.
- The timing of death, however, remains uncertain.
- In patients with advanced heart failure  
->60% died when expected to live for at least a further six months.

Levenson et al, 2000.

# End of life trajectory

Fig: Disease trajectories for people with cancer and those with COPD



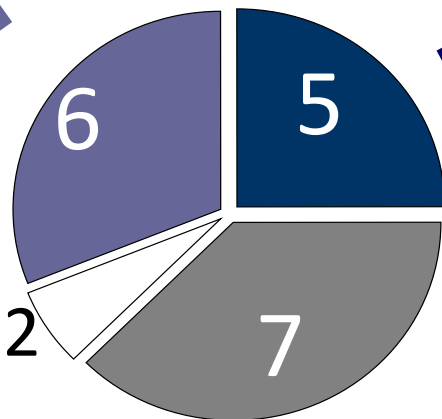
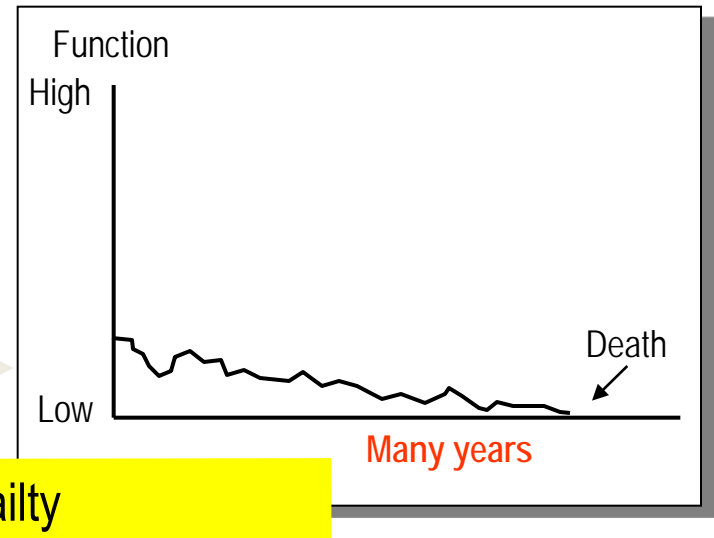
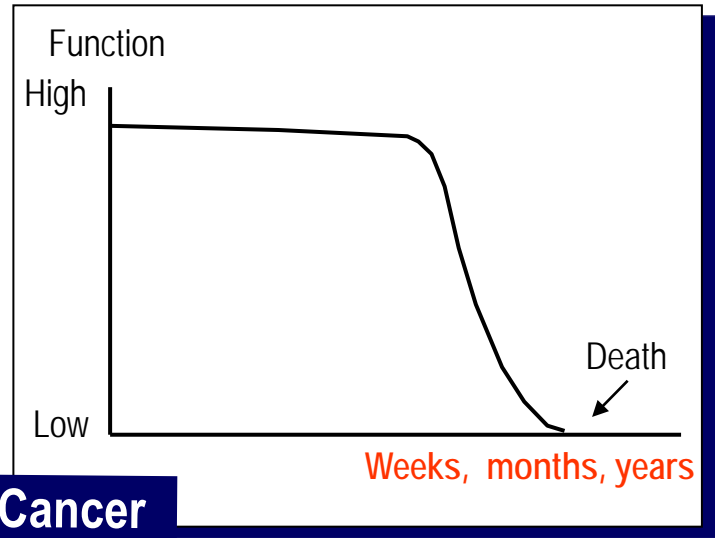
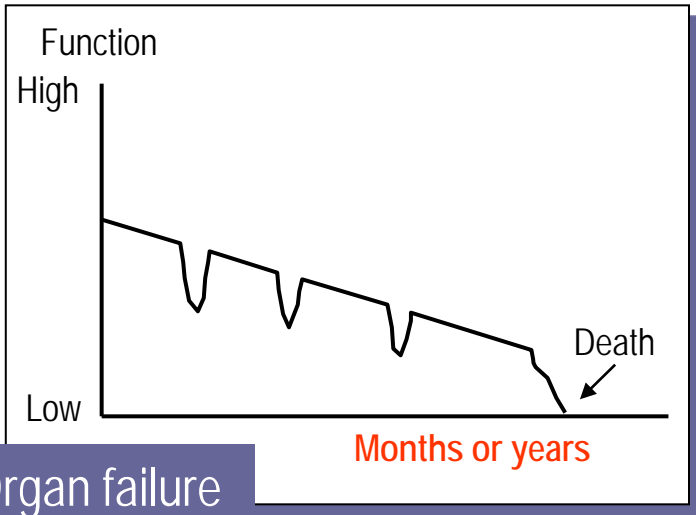
Strategy for Services for COPD in England / DOH Feb. 2010

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# End of life care for all?

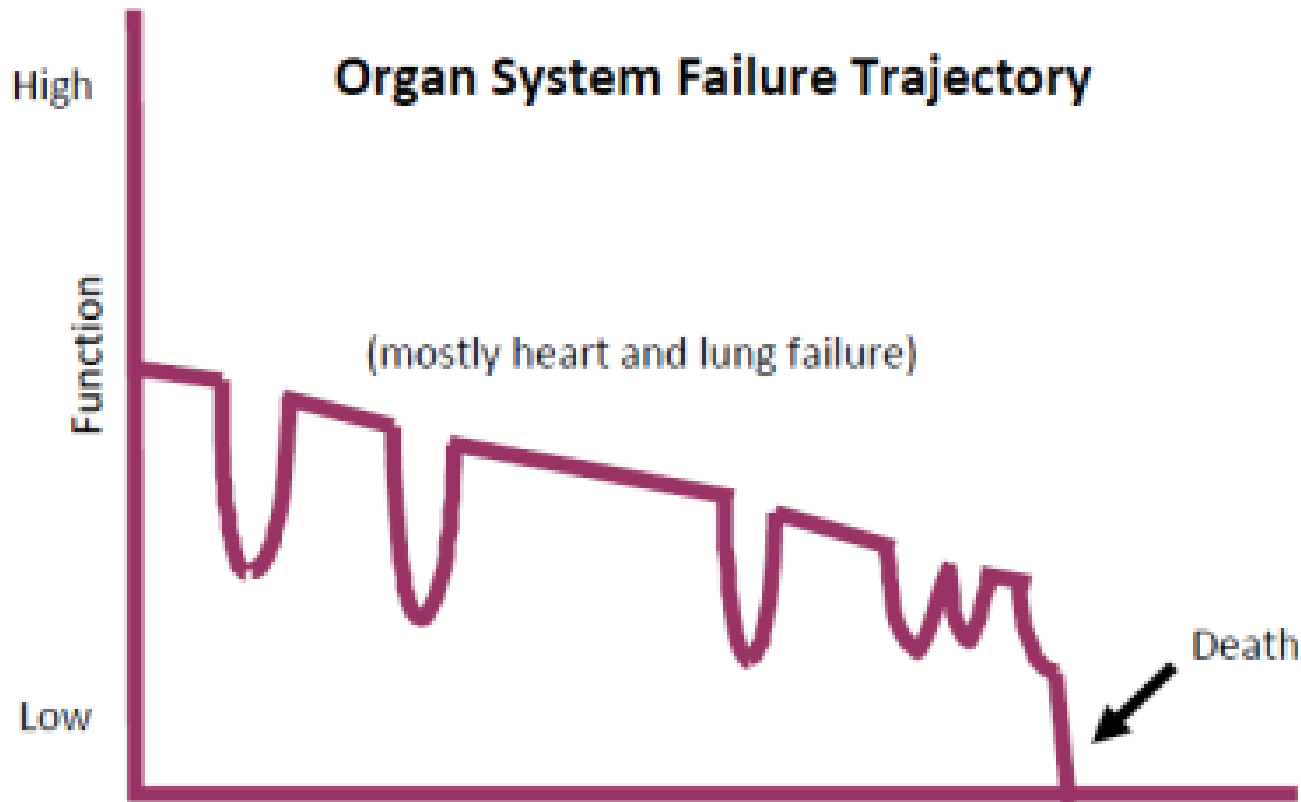
Murray PCC 2010



GP has 20 deaths per list of 2000 patients per year

Acute

# Organ Failure



Begin to use hospital often, self-care becomes difficult

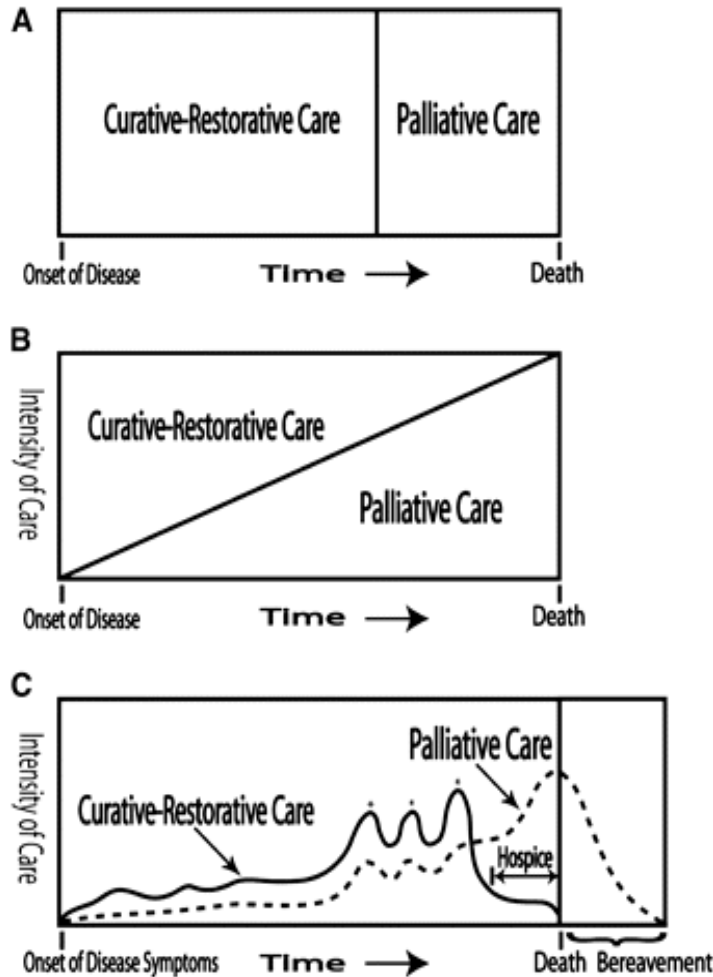


Time - 2-5 years, but death usually seems "sudden"

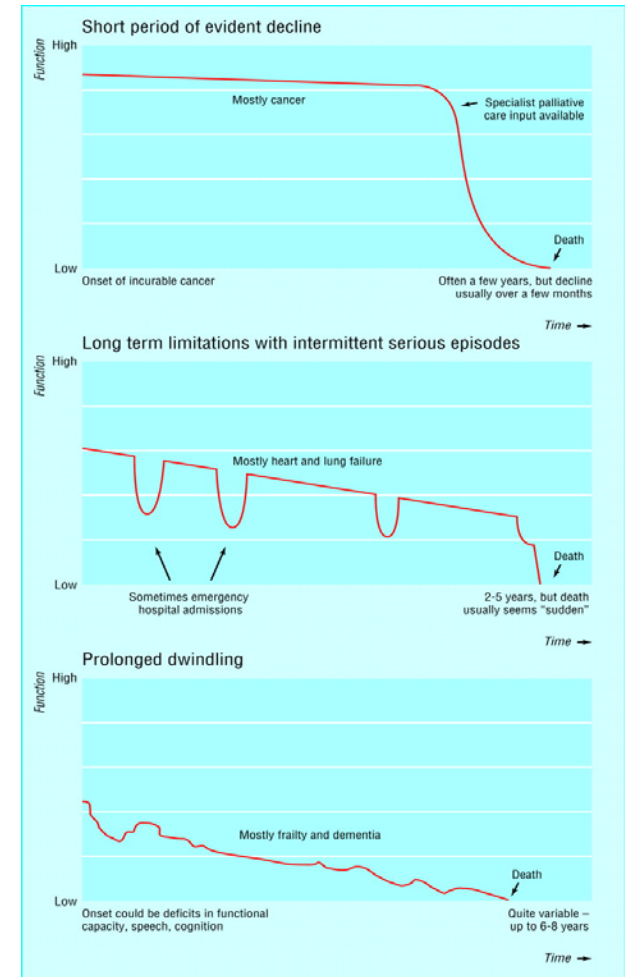
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# Models of care delivery

Lanken et al. 2008; Murray et al. 2005



**Needs mirrors the delivery model (integrated model)**



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Can we use any other tool?

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# Surprise question

- Dec' 2011-Feb' 2012
- 42 GPs- classified 231 patients (Italy)
- 126 patients –NO- wont be surprised
- 105- yes- will be surprised

Sensitivity	Specificity	PPV	NPV
69.3%	83.6%	83.8%	69%

- Moroni et al 2014. The 'surprise' question in advanced cancer patients: A prospective study among general practitioners. Palliative Medicine 2014;28(7) 959-964.

# O' Callaghan 2014

- New Zealand study- Hospital patients
- 501 Hospitalised patients.
- 56.6% Died in 6 months
- 68% died in 12 months.

	Sensitivity	specificity	PPV	NPV
12 months	62.6%	91.9%	67.7%	90%

- O'Callaghan et al 2014. Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting. Palliative Medicine .28(8):1046-1052.

	Died	Alive	Total
No	87 (83.6%)	39	126
Yes	17 (16.4%)	88	105

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# Comparison

	sensitivity	specificity
PSA (at 3)	59%	87%
Surprise Q	62.6%	91.9%
Surprise Q	69.3%	82.6%
Urine dipstick (Nitrates)	45-60%	85-98%
D-Dimer for DVT	74%	66%



# Defining End of Life:

Patient likely to die within next 12 months, including those whose death is imminent (few hrs or days) and those with:

- **Advanced, progressive, incurable conditions**
- **General frailty and co-existing 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"

*General Medical Council, 2010*

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# Systematic review 2014

- The challenges of uncertainty and inter-professional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.
- Ai Oishi and Fliss EM Murtagh Palliative Medicine 2014;28(9):1081-1098.

# Oishi 2014

- 30 studies - **719 patients, 605 carers and over 400 professionals.**
- Patients and carers expect primary care physicians to provide compassionate care, have appropriate knowledge and play central roles in providing care.
- The roles of professionals are unclear to patients, carers and professionals themselves.
- **Uncertainty of illness trajectory and lack of collaboration between health-care professionals were identified as barriers** to effective care.
- The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.
- Ai Oishi and Fliss EM Murtagh Palliative Medicine 2014;28(9):1081-1098.

# COPD– Poor Prognosis

- At least two of the indicators below:
- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

# SPICT (Supportive and Palliative care Indicators Tool)

- a clinical guide designed to help health and social care professionals identify people who are at risk of deteriorating and potentially dying with one or more advanced long term conditions

# COPD

- Severe chronic lung disease with:
- **breathlessness at rest or on minimal exertion** between exacerbations.
- Needs long term oxygen therapy.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.
- SPICT website ([www.spict.org.uk](http://www.spict.org.uk))

# Heart Failure: Indicators of Poor Prognosis

- NYHA III / IV, refractory symptoms despite OMT
- 3 or more hospital admissions last 6 months
- Dependent for more than 3 ADLs
- Advanced age
- Co-morbidities
- Cardiac Cachexia
- Albumin < 25
- Resistant hyponatraemia
- Multiple shocks from ICD

- *End of life care in heart failure: A framework for implementation; NHS Improvement 2010*

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# SPICT

- NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:
- breathlessness or chest pain at rest or on minimal exertion.
- SPICT website ([www.spict.org.uk](http://www.spict.org.uk)) for information and updates.



# Neurological conditions

## Conditions

- MND
- Multiple Sclerosis
- Parkinsons

## Indicators

- Rapid deterioration
- Intractable complex symptoms
- Complex Psychosocial needs
- First episode of aspiration pneumonia

# Triggers

- Marked decline in physical function
- Dysphagia
- Aspiration pneumonia
- Infection
- Cognitive impairment
- Weight loss
- Complex symptoms
- pain

# What can Palliative care do?

- Review of symptoms
- Psychosocial support
- Help with Advance Care Planning (ACP)
- Respite

- Hussain et al 2014. Triggers in advanced neurological conditions: prediction and management of the terminal phase. *BMJ Supportive & Palliative Care*. 2014;4:30-37.

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# Symptom control

Advance Care Planning

COPD- Morphine, Lorazepam,

Physio

CCF: Furosemide in syringe driver

Neurology- spasms,

communication

# Specialist palliative care: potential models

- Hands-off advice.
- One-off consultative visits/Out Patients
- Short-term involvement (Day therapy).
- Long-term involvement.
- (inpatient admissions, Respite care, Home care support, combined care with GP)

# In summary

- Trajectories need to be better defined and better understood
- Collaborate across boundaries and disciplines
- Palliative care itself needs to develop increasing flexibility and adaptability
- Recognise dying **OR**
  - **Enable the Living**
- Exploring preferences and priorities

# When is a patient palliative OR in need of a palliative care approach?

- Would you be surprised if Mrs A were to die within the next 12 months?
- Study in cardiology ward revealed that this question identifies 60 -70%.
- **Avoid “prognostic paralysis” \***

\*Murray SA, Boyd K, and Sheikh A. Palliative care in chronic illnesses: we need to move from prognostic paralysis to active total care. *BMJ* 2005. 330:611-12.

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Discussion...

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# Consultant mobile numbers

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for families facing terminal illness