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(Plenary)

17:30 - 17:50 Endstage care

Advanced COPD Management

Dr Rachel Wiseman Respiratory and Palliative
Care Physician

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Presentation Outline

- Setting the scene
 - Identification of patients
 - Coordination of care
 - Transition to a palliative approach
 - Integration of specialist palliative care
 - Advance Care Planning
- Conclusion and questions



Setting the scene

Living
with,
not
dying
from
COPD.



Setting the scene

- COPD is a progressive, life-limiting illness
- One of the highest causes of death worldwide
- Significant symptom burden
- Psychological symptoms are prevalent
 - Increased rates of anxiety, depression and panic
 - Social isolation and loneliness well documented
 - Loss of intimacy and sexuality
- Impact on carers under-recognised



Symptom Burden

Symptom %	Cancer	COPD	ILD	CF
Dyspnoea	10-70	90-95	98	64-100
Pain	35-96	34-77	36	63-84
Fatigue/malaise	32-90	68-80	29	54
Insomnia	9-69	55-65	7	
Anorexia/weight loss	30-92	35-67	18	
Headache				43
Cough/difficulty expectorating sputum				69-84



They live day by day

**They have adapted over
years**

**The past and the present
merge in their memory**

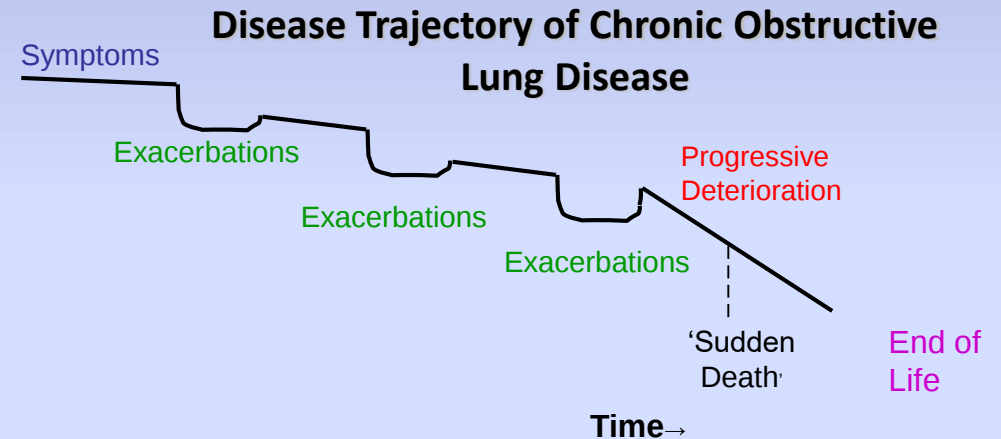
**Its hard to visualise a
different future**

**A “chaotic narrative”
(Pinnock)**

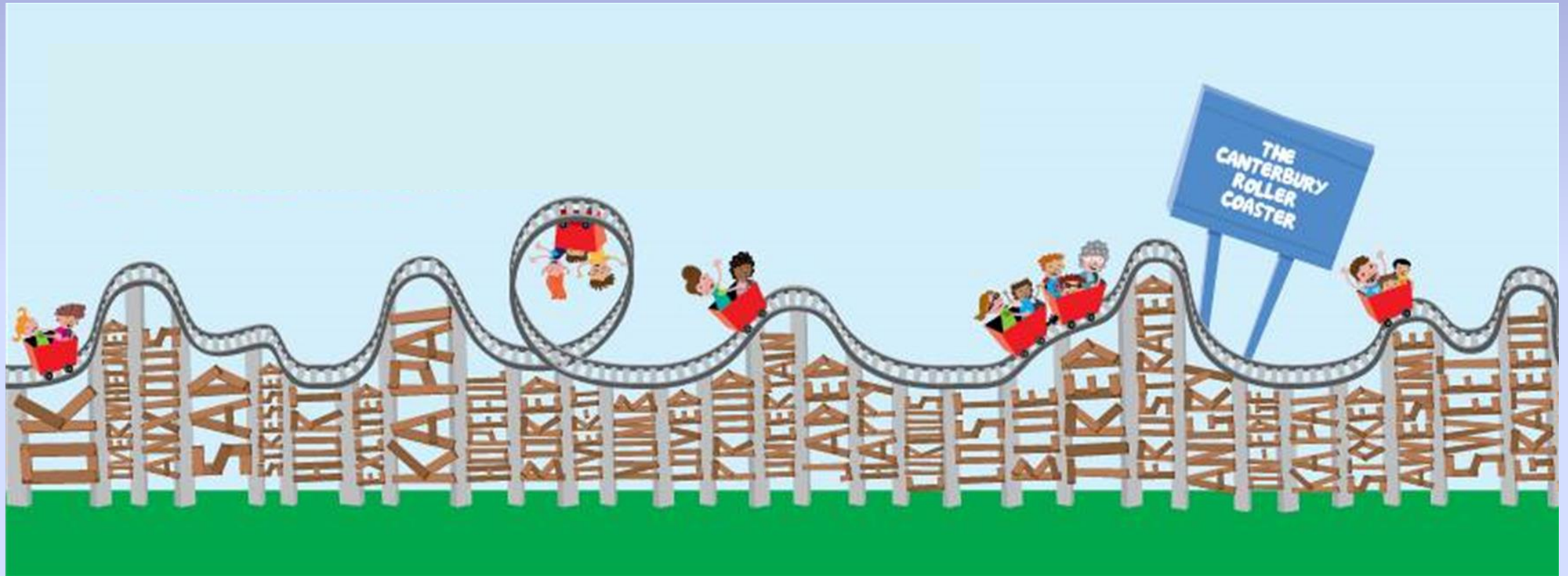
IDENTIFICATION OF PERSONS WITH ADVANCED COPD

Disease progression... identifying the 'tipping point'

- How long have I got?
years...months...weeks... days...hours?
- When is the patient approaching the 'terminal phase?'
- Universally difficult in COPD patients
- No one has yet found an answer.....



Trajectory of non-malignant disease



Physicians are not good at estimating survival....

- SUPPORT study – 5 days before death, physicians estimated that >50% of COPD patients would be alive in 6 months, compared to <10% of lung cancer patients
- 44% of bereaved relatives of COPD patients were not aware their loved one might die

Clinical Indicators/ General

- Multiple co-morbidities
- Weight loss, 10% over 6 months
- General physical decline
- Serum Albumin < 25g/l
- Reducing performance status, < 50% dependence in most ADLs



Specific Clinical Indicators

- Disease assessed to be severe e.g. FEV1 < 30% predicted
- Recurrent hospital admissions (>3 admissions in 12 months)
- Fulfils LTOT criteria
- Signs and symptoms of right sided heart failure
- Combination of other factors e.g. anorexia previous ITU/NIV/resistant organism, depression

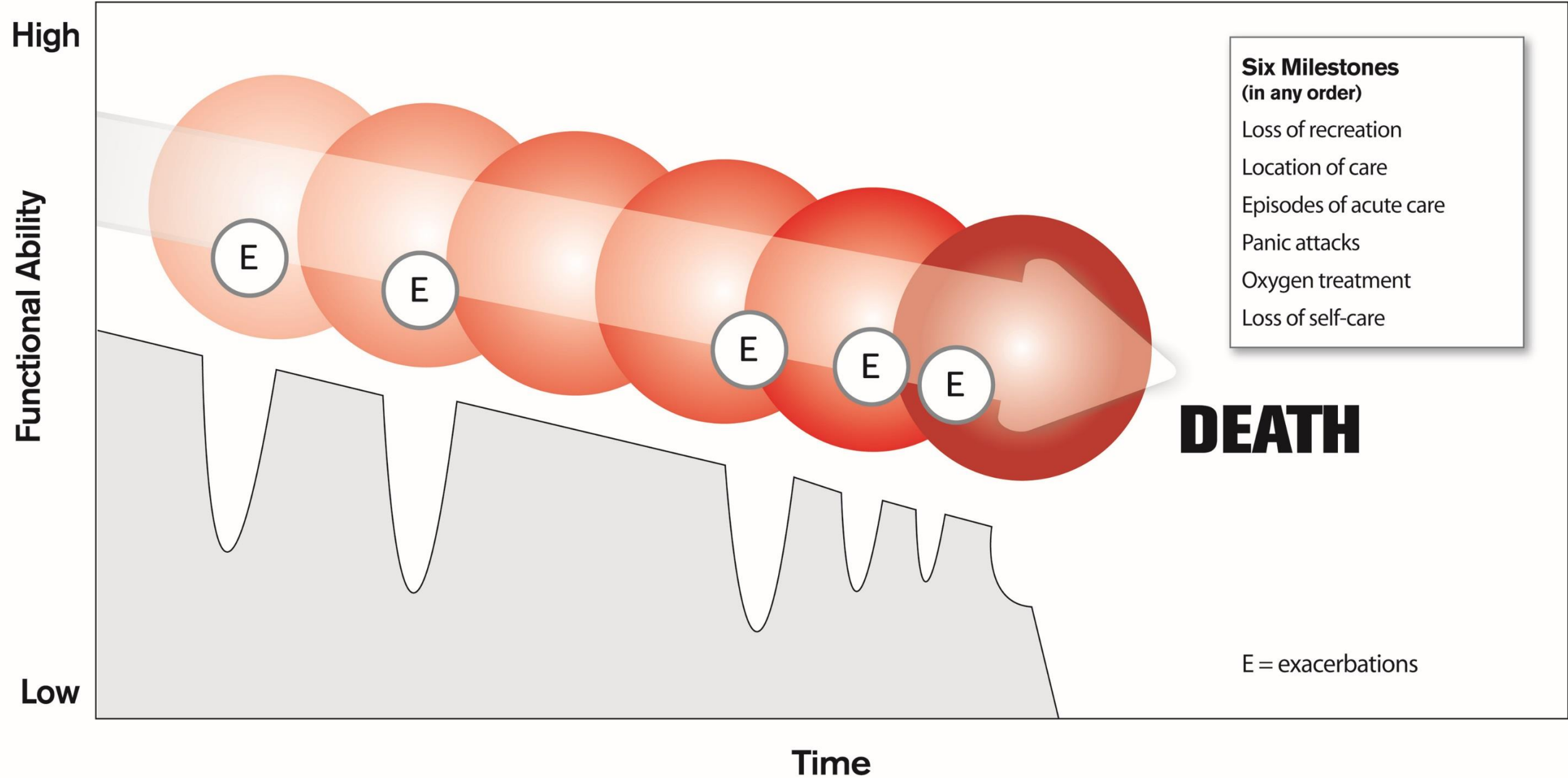
My 'Red flags'



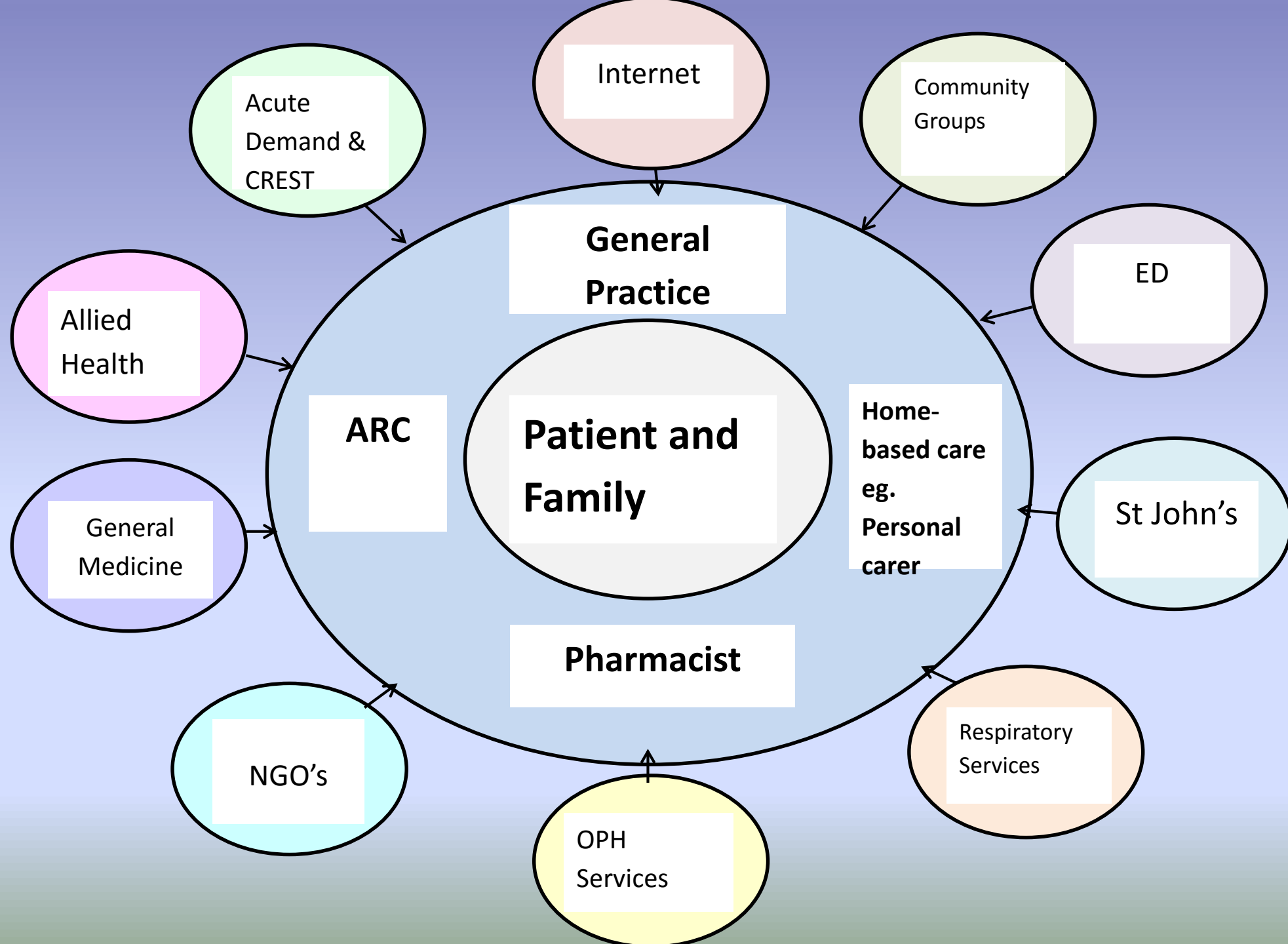
- ▶ “Antibiotics aren’t really helping anymore”
- ▶ “I panic”
- ▶ “Feel like I am smothering”
- ▶ “Too frightened to go to sleep because I may not wake up”
- ▶ “I don’t want to go to hospital anymore”
- ▶ “Am I going to choke to death?”
- ▶ “The inhalers aren’t helping any more”

Patient perceptions of severe COPD and transitions towards death: a qualitative study identifying milestones and developing key opportunities

Trajectory of Chronic Obstructive Pulmonary Disease



CO-ORDINATION OF CARE



TRANSITION TO A PALLIATIVE APPROACH

What is palliative care?

The World Health Organization (2003) defines palliative care as:

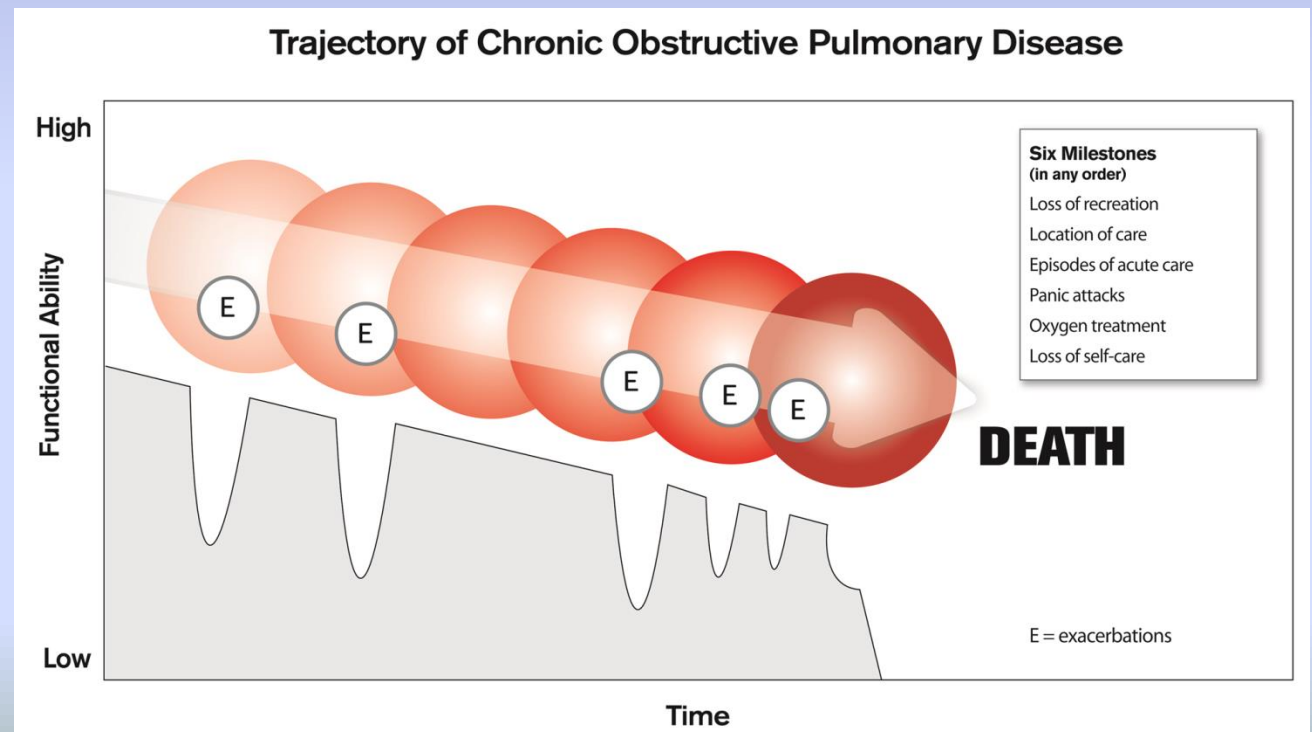
“An approach that improves the quality of life of individuals and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

Three Forms of Palliative Care

- **Palliative approach**
- **Specialist Palliative Care Services**
- **End of life (terminal) care**

The Three Triggers for Supportive/Palliative Care

1. The Surprise question
2. Clinical indicators
3. Choice/ need
4. Milestones



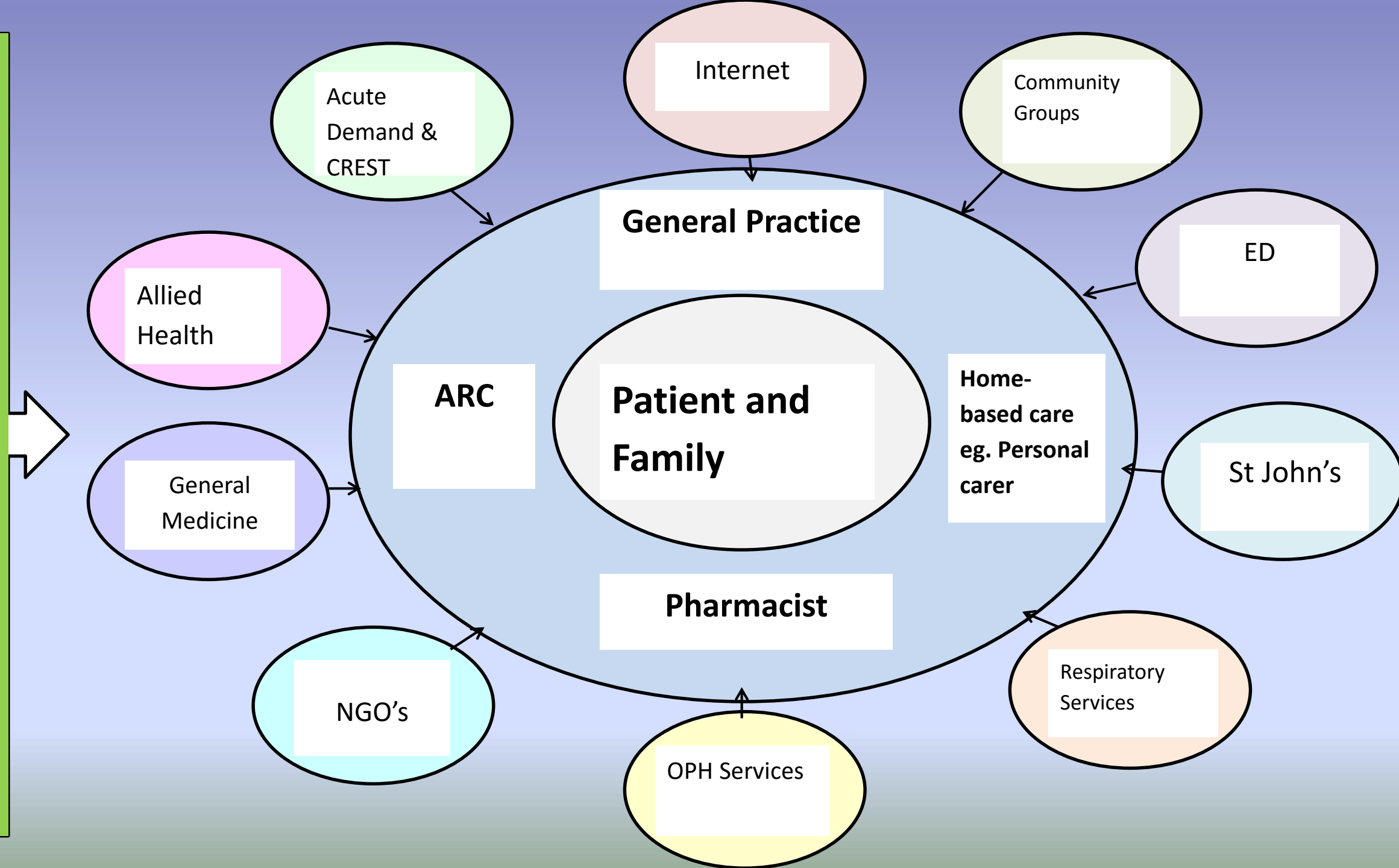
INTEGRATION OF SPECIALIST PALLIATIVE CARE

New model of health care delivery?

Where does palliative care sit?

- PC offers a different approach which may be missing from other parts of the health system focussed on acute care
- Patients want more information about lung disease and trajectory

SPECIALIST PALLIATIVE CARE



ADVANCE CARE PLANNING

Advance Care Planning in COPD: the challenges

‘Talking about sex doesn’t make you pregnant, talking about dying doesn’t make you dead’

‘Right time, right place, right person’



Decision-making

- COPD patients find it hard to imagine future scenarios where their health may deteriorate
- Therefore they find it difficult to make 'concrete' decisions about care in advance

BUT:

- They are able to discuss general preferences for care
- Place of care is often strongly considered – influenced by previous experiences in hospital

Integration of ACP

- Little evidence about how and when to integrate ACP into COPD care
- 2 approaches:
 - Routinely discuss ACP at each opportunity
 - Discuss ACP when specific triggers arise
 - initiation of home oxygen, pulmonary rehabilitation, admission for BiPAP
- Prepare patients to make the best possible ‘in the moment’ decisions
- Creating opportunities

Conclusion



A journey with no
beginning.....
and thus no
end.....