MANAGING PATIENTS WITH END-STAGE NON-MALIGNANT RESPIRATORY DISEASE: WHAT THE PALLIATIVE CARE TEAM CAN OFFER

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14 November 2019

TAKING PRIDE IN OUR CARE

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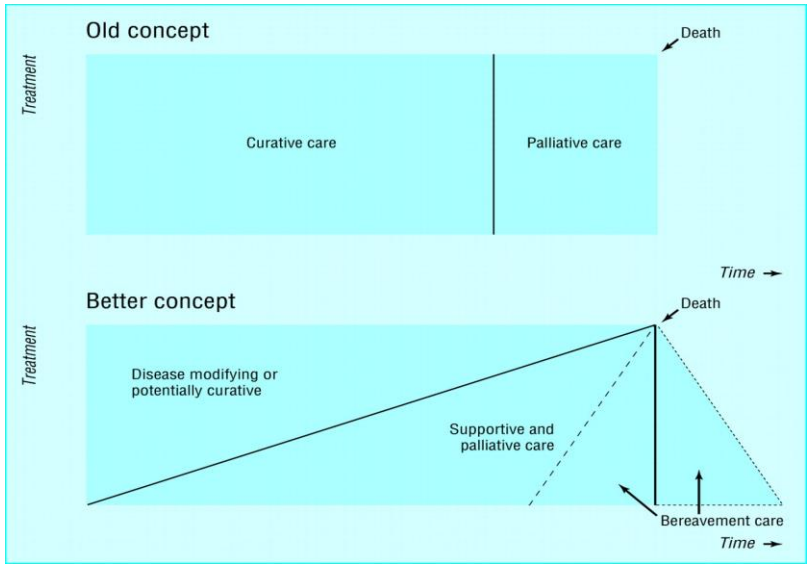
SCOPE OF TALK

- An outline of the symptom burden of non-malignant respiratory disease
- Symptom management
- Advance Care Planning (ACP)
- Case study

WHAT IS PALLIATIVE CARE?

- The active holistic care of patients with **advanced progressive illness**.
- Includes the management of pain and other **SYMPTOMS** and the provision of **PSYCHOLOGICAL, SOCIAL** and **SPIRITUAL** support.
- The aim is to achieve the best possible quality of life (QoL) for **patients** and **their families**.
- Many aspects are applicable earlier in the course of the illness in conjunction with other treatments.

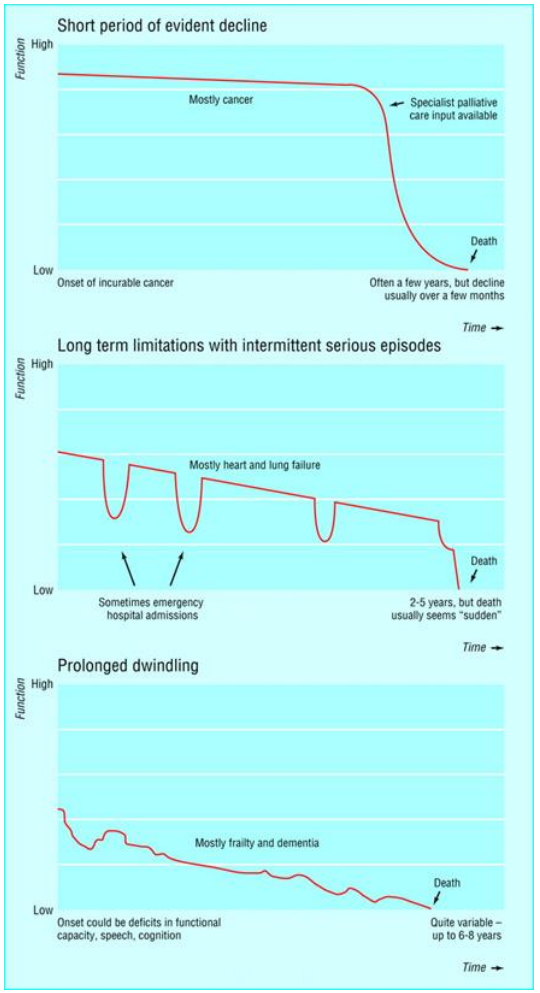


Murray S A et al. BMJ 2005;330:1007-1011

THE CHALLENGES FOR US!

- Palliative care service provision for CRD patients is variable.
- End of life care decisions are often suboptimal and rarely initiated with patients or their carers.

  (Gore JM et al., 2000, Knauft E et al. 2005 & Curtis JR et al. 2004)
- Recognition of the importance of good palliative care for all people who need it regardless of diagnosis.
- People with COPD have at least as severe if not more severe symptoms than someone with lung cancer.
- Prognosis of CRD difficult to predict.



SYMPTOM PREVALENCE IN COPD

Distressing symptoms	COPD (%)	Lung cancer (%)
Fatigue	70-95	50-60
Breathlessness	60-95	45-75
Cough	60-80	30-80
Insomnia	55-75	10-60
Anxiety	30-75	10-45
Pain	20-80	50-90
Depression	15-75	15-70
Anorexia	10-80	35-75
Constipation	25-45	30-60
Nausea	5-45	15-45

Elkington H, White P, Addington-Hall J, et al. (2005) The Health Care Needs of Chronic Obstructive Pulmonary Disease Patients in the Last Year of Life. Palliat Med; 19:485-491

BREATHLESSNESS

- Dyspnoea – “a subjective awareness of breathing discomfort”

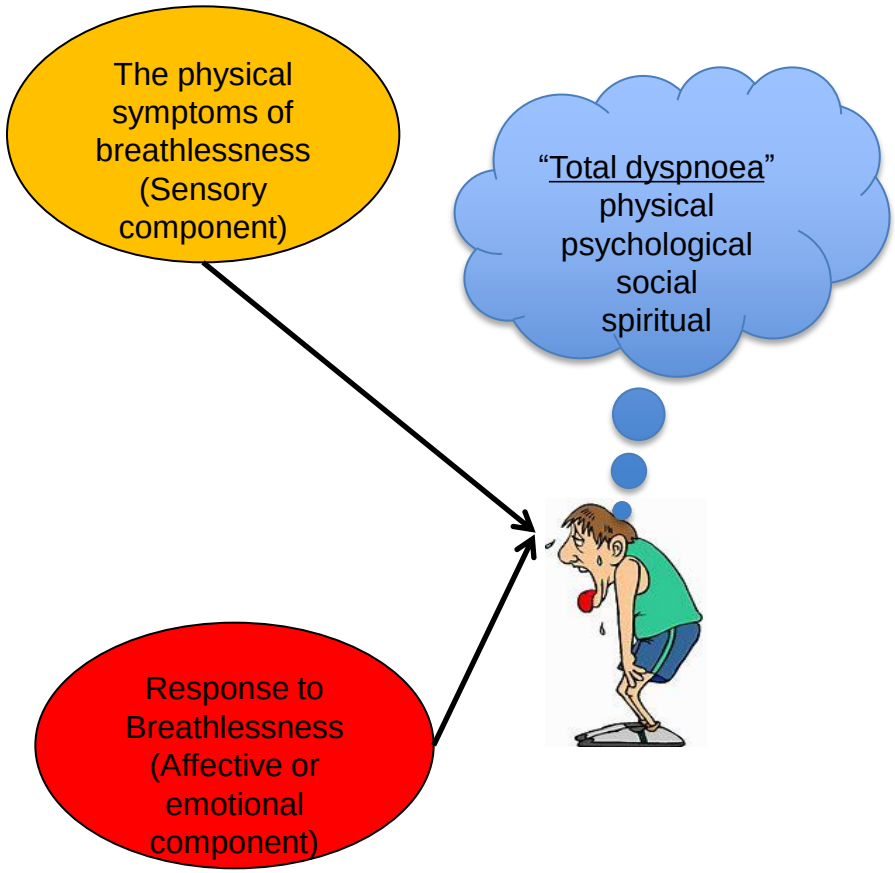
American Thoracic Society. Am J Respir Crit Care Med1999 ;159: 321-340

- Present in
- > 60% of patients with advanced heart failure
- ~ 70% of patients with advanced malignancy
- > 90% of patients with COPD

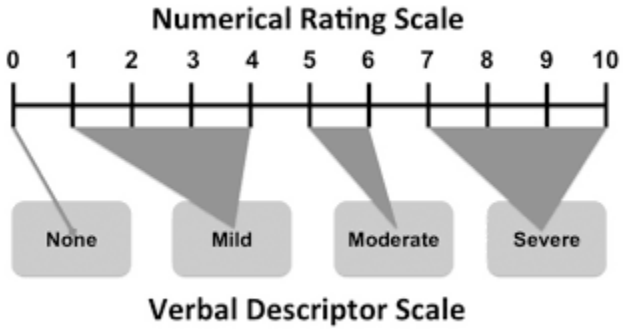
Bausewein et al Resp Med 2007; 101(3):399-410

- The pathophysiology of breathlessness is complex and not fully understood.
- It is stimulated by mechanoreceptors in airways, lung parenchyma, intercostal muscles and the diaphragm.
- Hypoxia and high levels of CO2 detected by chemoreceptors in aortic and carotid bodies and medulla oblongata.
- *Management of breathlessness calls for an understanding of the multidimensional nature & pathophysiological mechanism causing distress*.

“TOTAL DYSPNOEA”

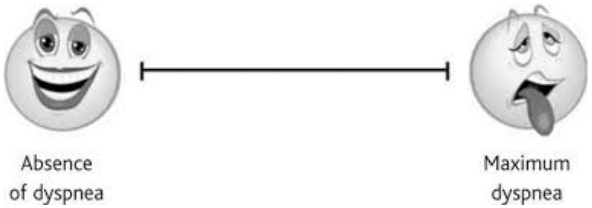


ASSESSMENT OF BREATHLESSNESS



The MRC Breathlessness Scale

Grade	Degree of breathlessness related to activities
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying on the level or walking up a slight hill
3	Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at own pace
4	Stops for breath after walking about 100 yds or after a few minutes on level ground
5	Too breathless to leave the house, or breathless when undressing



Modified Borg Scale

Rating	Intensity of sensation
0	No symptoms
0.5	Very, very slight sensation of symptoms
1	Very Slight
2	Slight
3	Moderate
4	Somewhat Severe
5	Severe
6	
7	Very Severe
8	
9	Very, Very Severe
10	Maximal

Table 2: Modified Borg Scale from Borg G: Psychophysical bases of perceived exertion. Med Sci Sports Exerc 1982;14:377-381.

DRUGS FOR BREATHLESSNESS

- Bronchodilator therapy should be optimised in accordance with NICE guidance.
- Opioids- orally/parenterally
- Anxiolytics. Anxiety can exacerbate breathlessness. Clinical experience suggests that low-dose anxiolytics (diazepam) can result in improvements despite a lack of evidence. Sublingual lorazepam can be used.
- Antidepressants. TCA's and serotonin selective reuptake inhibitors have been shown to be beneficial.
- Nebulised opioids-**no** good evidence to support use

APPROACHES TO BREATHLESSNESS

Non-drug

Pulmonary Rehabilitation:

- improves exercise capacity
- improve subjective dyspnoea
- improve quality-of-life
- reduce hospitalisations and health care utilisation
- decrease anxiety and depression

Fan

Anxiety reduction techniques

Psychological interventions

“Breathtaking Groups

Exercise/ breathing exercises.

Energy conservation (pace activities)

Drugs

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OPIOIDS – FOR REFRACTORY BREATHLESSNESS

- Consistent evidence that opioids reduce the sensation of breathlessness.
- There is no evidence to date that the doses of opioids used to palliate breathlessness causes clinically detectable respiratory depression or increased mortality.
- A large safety study in COPD patients is urgently needed
- Opioid should be started at a low dose and titrated up carefully with appropriate monitoring.

"End of life care in chronic obstructive pulmonary disease: in search of a good death." Anna Spathis and Sara Booth. International Journal of COPD 2008:3 (1) 11-29

OPIOIDS – FOR REFRACTORY BREATHLESSNESS

Immediate-release (i/r) morphine approach

- 1st week – start with 0.5mg PO bd and increase at 48h intervals
  - → 0.5mg qds
  - → 1mg q4h
- Then at weekly intervals , increase the q4h dose to 2mg then 3mg then 5 mg
- If necessary continue to adjust each week using 30-50% dose increments
- Reduce dose if undesirable s/e occur
- If s/e persistent consider opioid switch
- When the dose is unchanged for 2 weeks then consider switching to m/r formulation

Modified-release (m/r) morphine approach

- Start with MST Continus® 5mg PO bd for 1 week.
- If baseline breathlessness not reduced by ≥ 10% increase by 10mg/24h weekly
- Usual maximum dose 30mg/24 hrs.

Palliative Care Formulary (PCF) 2017

Remember - antiemetic/laxative provision!

BREATHLESSNESS IN THE LAST FEW DAYS

- Patients often fear suffocating to death.
- Utilize drug treatment correctly to relieve terminal breathlessness.
- Drug-related drowsiness may need to be the price paid for greater comfort.
- Communicate with family.
- Parenteral administration - for opioid naïve patients:

CSCI: morphine 5-10mg/24hr + midazolam 5- 10mg/24h
PRN: morphine 2.5mg + midazolam 2.5mg SC prn q1h

- Titrate both prn and regular doses to obtain symptomatic relief.
- Levomepromazine or haloperidol if agitated delirium is present.
- Remember to prescribe the other anticipatory PRN drugs

OXYGEN

- Prescribed for hypoxaemic patients (SpO2 ≤ 92%) to:

  increase alveolar oxygen tension

  decrease the work breathing necessary to maintain a given arterial oxygen tension

- National Guidelines (2011- Home Oxygen Service assessment & review. 2015 BTS guidelines on Home O2)

  recommend that home oxygen should NOT be prescribed simply for the relief of breathlessness unless the patient has hypoxaemia (SpO2 ≤ 92%) and other treatment options are ineffective (e.g. opioids, breathing control, fan).

- Caution with patients with hypercapnic respiratory failure who are dependent upon hypoxia for their respiratory drive.

- N.B. nasal cannulae at 2 L/minute can give oxygen concentrations varying from 24-35%

Source: PCF 6 (2017)

COUGH

- If related to difficulty expectorating-Sodium chloride 0.9% nebules 2.5 - 5 mL prn to 1-2 hourly as needed
- Symptomatic relief-simple cough linctus 5-10mL qds
- Cough suppressants
- Codeine linctus (15 mg/5 mL) 5-10 mL up to qds
- Low-dose morphine
- Methadone linctus (2mg/5mL) initially 2mg nocte increasing to bd if necessary
- In the terminal phase-consider CSCI morphine sulphate (5-10 mg/24 hours)
- **Sputum management**
- Carbocisteine 750mg tds reducing to maintenance dose of 750 mg bd

PAIN IN RESPIRATORY DISEASE

- 1/3rd to 2/3rds of patients
- Often under assessed
- Causes:
- RTI – pleuritis, tracheo-bronchitis
- Rib #, costochondritis, muscle sprains,
- Muscle fatigue, PE

Management:

- Pharmacological:
- WHO - analgesic ladder

- Non- pharmacological:
- psychological therapies – CBT, relaxation, imagery/distraction techniques

FATIGUE

- **Fatigue** - common symptom (prevalence various from 45-80% in COPD. Very few studies investigating interventions that may help COPD-related fatigue-pulmonary rehabilitation has been found to give benefit.

- 2nd only to dyspnoea in prevalence (up to 80% of those with COPD)
- Negative impact on the quality of life
- Often neglected by medical staff
- Cytokines may be an underlying mechanism

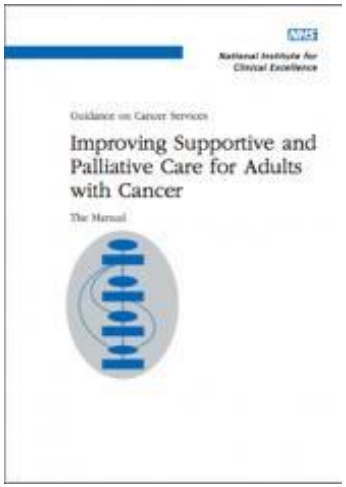
Management

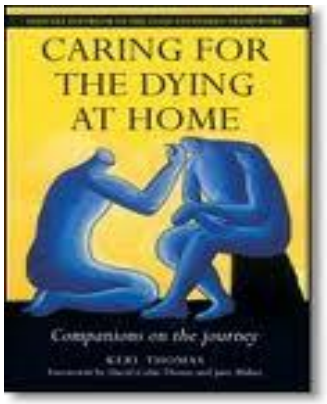
- Correct the correctable e.g. depression, breathlessness, pain, sleep disturbance, anaemia, coexisting infection.
- Consider a trial of corticosteroids (4/52 trial)
- ?role for methylphenidate
- Non pharmacological approaches
- Energy conservation techniques – prioritise and avoid unnecessary activities
- Adapting a particular task
- Relaxation techniques

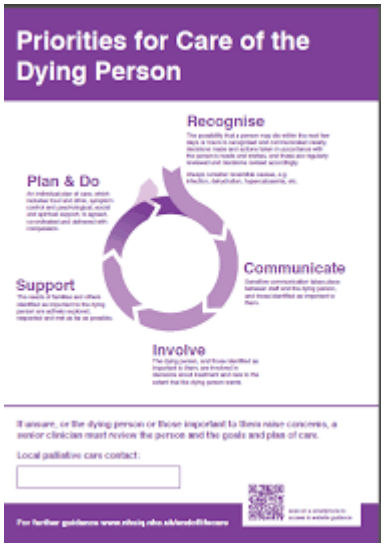
ANXIETY/DEPRESSION

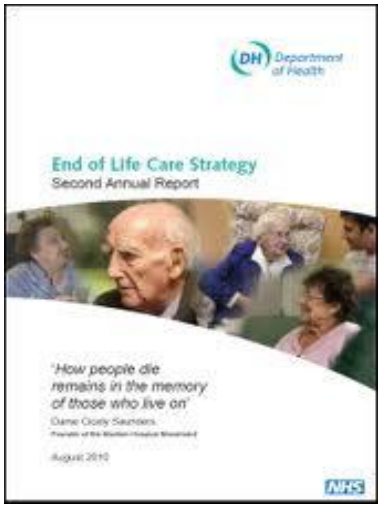
- **Anxiety and depression**-prevalence rates vary each between 20 to 50%. Evidence that approximately only 1/3 of patients are being treated.
- Anxiety is inextricably linked with breathlessness
- The mainstay of anxiety management is non-pharmacological-explore concerns, fears and expectations.
- Cognitive behavioural therapy (CBD) has been shown to improve anxiety and depression in advanced COPD. - Sage N, Snowden M et al 2008
- Benzodiazepines can be usefully in the short term to break the anxiety/dyspnoea cycle and restore sleep. The addictive potential is less of a concern when prognosis is short.
    - Lorazepam 0.5mg SL – useful for PRN use
    - Diazepam 1-5mg nocte
    - Midazolam for CSCI
    - Antidepressants with anxiolytic properties may be helpful e.g. amitriptyline, mirtazapine, paroxetine and citalopram. Buspirone may have a role

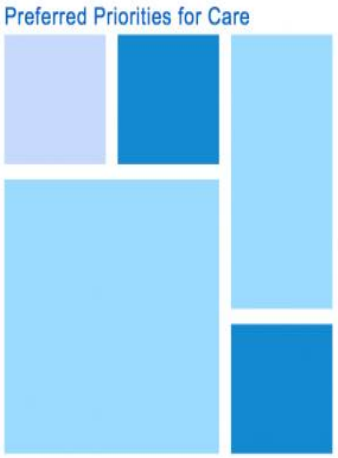
END OF LIFE CARE/ ACP - GOVERNMENT AND NATIONAL PRIORITY











GSF PROGNOSTIC INDICATOR GUIDANCE

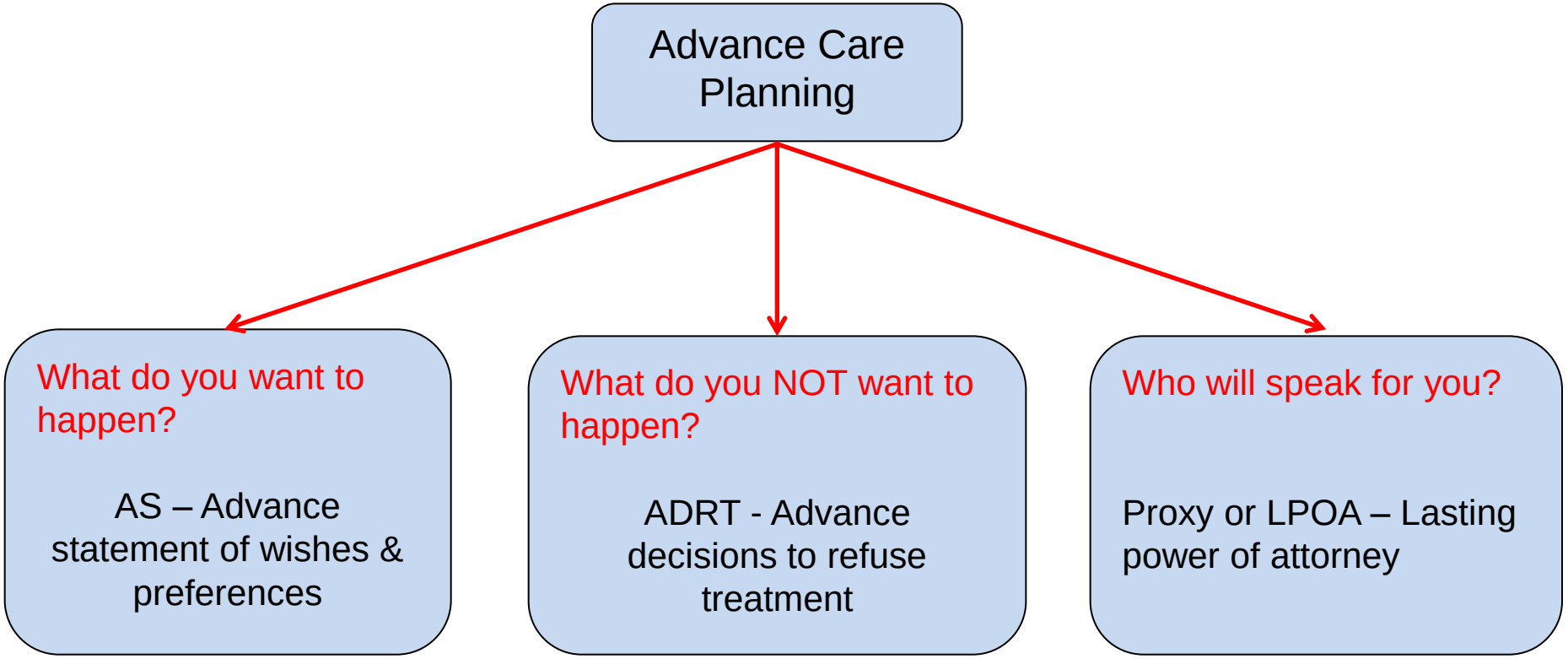
The 3 “triggers” for supportive/palliative care

1. The “surprise question”. Would you be surprised if this patient were to die in the next 6 to 12 months.”

2. Choice/need. The patient with advanced disease makes a choice for comfort care only, not curative treatment, or is in special need of supportive/palliative care.

3. Clinical indicators -specific for the advanced disease

ADVANCE CARE PLANNING (ACP) DISCUSSIONS



www.goldstandardsframework.org.uk/advance-care-planning

THE GSF PIG 2016 – PROACTIVE IDENTIFICATION GUIDANCE

Chronic Obstructive Pulmonary Disease (COPD)

At least **two** of the indicators below:

- Recurrent hospital admissions (at least 3 in last year due to COPD)
- MRC grade 4/5 – shortness of breath after 100 metres on level
- Disease assessed to be very severe (e.g. FEV1 <30% predicted), persistent symptoms despite optimal therapy, too unwell for surgery or pulm rehab.
- Fulfils long term oxygen therapy criteria (PaO2<7.3kPa).
- Required ITU/NIV during hospital admission.
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, requires palliative medication for breathlessness still

  smoking.

FROM THE BMJ JANUARY 2011

PINNOCK ET AL "LIVING AND DYING WITH SEVERE COPD-MULTI-PERSPECTIVE LONGITUDINAL QUALITATIVE STUDY"

- Postulate that COPD patients "**passively accept**" their lot and see the increasing disability as part of normal ageing. (In contrast to cancer and heart failure)-**lack the "narrative story."**

- Suggested potential "**transition points**" (to prompt professionals to open discussions) e.g.

  at the point of diagnosis

  the time of retirement for medical reasons

  the point at which domiciliary oxygen is needed or during hospital admissions

BARRIERS TO COMMUNICATION ABOUT END OF LIFE ISSUES IN COPD

INTERNATIONAL JOURNAL OF COPD 2008:3 (1) 11-29 SPATHIS, BOOTH

•Healthcare professional barriers

•Difficulty in timing discussions because of uncertain prognosis

•Lack of time during consultations

•Concern about taking away patients' hope

•Belief that patients are not ready to discuss end of life issues

•Patient barriers

•Expectation that healthcare professionals will initiate discussions

•Societal taboos with regard to discussing death

•Uncertainty about which professionals will be involved during end of life phase

•Lack of certainty about type of care that would be wanted when less well

CASE STUDIES

CASE 1

- Mr AJ-78 years old, retired schoolteacher
- 12 year history of COPD
- Resident in nursing home for three years
- Advance care plan in place having had successive exacerbations treated by hospital admissions-wants hospitalisation and resuscitation in the event of cardiac arrest.
- Admitted to hospital with an exacerbation-low oxygen levels, chest x-ray revealing extensive damage and infection. After eight days of antibiotics and steroids, on-call doctor recommends NIV
- Over the next four days, Mr AJ takes the mask of constantly and this is documented in the notes as his refusal of treatment and being non-compliant.
- **Could this case have been handled differently?**

THOUGHTS ON CASE 1

- ACP in place already – appropriate for his current circumstances.
- "Thinking Ahead" – document – what's important to the patient?
- PEACE document

•Revisit ACP – in hospital 8 days before NIV initiated (by on-call Dr) - ?? Acute deterioration or more gradual.

•Decisions best made by his usual team if possible??

- Does patient have capacity?
- or "best interests" decision making
- NOK available if not IMCA

- NIV – different mask types. ?? low O2 causing muddle

- NIV initiation
- What does the patient want?
- Careful advance care planning is vital. Any patient commenced on NIV should be involved in discussion about potential discontinuation, before NIV is commenced.
- May come a time when NIV is offering no benefit and continued treatment would be futile. Ensure safety-net drugs in place – midazolam/opioid CSCI as appropriate.

- PLANNING involving DISCUSSION/COMMUNICATION

CASE 2

- Iris-74-year-old with COPD. On continuous oxygen. Lives with husband.
- Well known to the respiratory CNS
- Recent decision following several admissions to hospital that she no longer wanted to be hospitalised in the event becoming unwell.
- Developed exacerbation of COPD, Iris expressed the wish to stay at home- treated with antibiotics and steroids and seen by the palliative care team. Oramorph commenced, family coped well and Iris got better!
- Two months later further exacerbation over a weekend, husband couldn't contact respiratory CNS, panicked and rang 999. Patient ended up admitted and on NIV. On the Monday morning, the respiratory CNS found a very distressed Iris and following discussions with medical team and her husband, the NIV was stopped and Iris was made comfortable. She died later that day.
- **How could things have been improved?**
- **What was lacking?**
-

THOUGHTS ON CASE 2

- Key worker
- Contact numbers readily to hand
- Safety-net drugs available in house with authorisations

- Communication between primary and secondary care / LAS etc – Coordinate My Care (CMC)

CASE 3

HOSPITAL IN-PATIENT WITH SEVERE COPD REQUIRING NIV

- Mr K.E. 65 year old gentleman with severe COPD
- BACKGROUND
- 2008 – commenced LTOT
- Increasingly housebound
- Wife-sole carer
- Admission with an exacerbation of COPD (1st admission for 7 years!)
- Type II respiratory failure
- Required High Dependency Unit (HDU) and NIV
- Attempted wean from NIV x 2 thwarted by an increase in breathlessness & anxiety

•Referred to Hospital Macmillan SPC team

- Wearing NIV facemask 24/7 except for brief periods for eating
- NRS score 8/10 off NIV and 5/10 on NIV ("NIV makes me feel much better")
- Commenced on lorazepam 0.5 mg BD initially and encouraged to try low dose opioid (oxynorm 0.5 -1mg –initially PRN). (Expressed worries about addiction etc)

•PLAN: referral to London Chest for NIV at home assessment.

•Assuming that he's suitable for NIV at home how would you plan his discharge and safe return to the community?

THOUGHTS ON CASE 3

- Advance care planning needed.
- -What are the patient's wishes
- -ceilings of care ? Further hospital admissions
- Palliate at home/hospice
- -funding for P.O.C. etc
- -safety-net drugs & authorisations

- Community support –pre-discharge planning meeting
- -key worker
- -community respiratory team
- -who to contact re: NIV settings if needed
- -district nursing service

THE NATIONAL COUNCIL FOR PALLIATIVE CARE RECOMMENDATIONS

- A collaborative approach across localities and settings of care to ensure improvement of patient and carer outcomes.
- Development of a local care pathway/end of life care pathway
- Quality Outcomes Framework registers within primary care that potentially could link to supportive care registers
- People with CRD and their carers should have a single point of contact (probably community-based)
- Befriending services should be available to carers throughout the illness and for bereavement support afterwards
- Advance care planning should begin early in case of future loss of capacity
- Workforce development-communication skills, assessment, symptom management and advance care planning