Identification of Patients Entering End Stages of Chronic Obstructive Pulmonary Disease (COPD)

NHS Calderdale CCG, NHS Greater Huddersfield CCG, NHS North Kirklees CCG, NHS Wakefield CCG Mid Yorkshire NHS Hospitals Trust and Calderdale and Huddersfield Foundation Trust

Working with patients who have severe COPD?

- Identify a point at which end of life issues should be discussed.
- **Please note:** Active treatment for exacerbations and management of symptoms should continue. These should be complemented by supportive and palliative care therapies.
- It is important to recognise that the prognosis for those with COPD is difficult to predict. As no definitive index exists, all indicators included in this document, subjective and objective, are of equal value in supporting the identification of patients entering the end stages of COPD. Equal weight should be given to their use.
- End of life discussions and the use of supportive and palliative care approaches should be considered for patients who request or wish to discuss such issues at any stage of their disease.

Respiratory Clinical Indicators

- Surprise question *'Would you be surprised if this patient were to die in the next few months, weeks, days'*
- Severe disease (FEV1 <30-35%)
- Reduced function (walking less, housebound, unable to do ADLs)
- Increased symptoms (MRC Dyspnoea score 4-5, breathless at rest, persistent severe symptoms)
- Low BMI (<21)
- Increasing exacerbations (>2-3 a year, decreasing intervals between, increased hospital admission, limited improvement post admission)
- Use of Non Invasive Ventilation (NIV), patient unwilling to continue NIV long term or refuses in acute exacerbation
- On maximal therapy
- On LTOT or ambulatory O_2 (or meets criteria)
- - Severe co-morbidities including symptomatic right heart failure

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. FEV_1 <30% predicted), persistent symptoms despite optimal therapy, too unwell for surgery or pulmonary rehabilitation.
- Fulfils long term oxygen therapy criteria ($Pa0_2$<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.

Supportive Care guide

- Review current care and care planning.
- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy
- Referral for specialist assessment if symptoms or problems are complex and difficult to manage is appropriate
- Agree a current and future care plan with the person and their family. Support family carers
- Plan ahead early if loss of decision-making capacity is likely e.g. lasting power of attorney, advanced decisions to refuse treatment
- Record, communicate and coordinate the care plan

Enquiries to:

NHS Calderdale CCG: Dr N Taylor (nigel.taylor@nhs.net)

NHS North Kirklees CCG: Sarah Sowden (Sarah.Sowden2@northkirkleesccg.nhs.uk)

NHS Greater Huddersfield CCG: Dr A Handa (Anuj.handa@nhs.net)

NHS Wakefield CCG: L Chandler (lisachandler@wakefield.gov.uk)

Group responsible for development: NHS Calderdale CCG, NHS Greater Huddersfield CCG, NHS North Kirklees CCG and NHS Wakefield CCG. Cross cluster respiratory group in collaboration with the Mid Yorkshire Hospitals NHS Trust and Calderdale and Huddersfield Foundation Trust and Locala CIC.

Published: September 2019 **Review due**: **September 2022** (unlessclinicalevidence basechanges)

Actions to be completed through the pathway.

Last year/s of life	Weeks to months	Last days to short weeks	After death
Supportive Care Register (GSF) EPaCCS	Supportive Care Register (GSF) EPaCCS	Supportive Care Register (GSF) EPaCCS	Verification of Death EPaCCS
Prognosis discussion	Prognosis discussion	Prognosis discussion	Offer bereavement mementos (hair locks, hand prints)
Advance Care Planning Involve patient and people important to them. Tissue Donation Information	Advance Care Planning Involve patient and people important to them. Tissue Donation Information	Advance Care Planning Involve patient and people important to them. Tissue Donation Information	Care After Death
Consider DNAR Update EPaCCS	DNAR Update EPaCCS	DNAR Update EPaCCS	Tissue Donation Information
Assessment, care planning and review Update EPaCCS	Assessment, care planning and review Update EPaCCS	Assessment, care planning and review Fast track discharge Update EPaCCS	Provide bereavement booklet
Finances- discuss and identify any concerns	Finances DS1500 Update EPaCCS	Commencement of EOL plan	Bereavement Support/Visit Signpost to providers
Blue badge permit	Anticipatory Medications	Anticipatory Medications	Update EPaCCS
Communicate with GP	Communicate with GP, DN's, OOH	Communicate with GP, DN's, OOH	Inform GP, OOH & all relevant agencies

End of life issues including advanced care planning, should be addressed by the treating clinician.

Referral to specialist palliative care or hospice services should be made for patients with Respiratory Disease, including COPD who:

- Has uncontrolled physical symptoms either related to COPD or any co-morbidity that are having a significant impact on their quality of life despite optimal medical management
- The patient has unresolved complex needs that cannot be met by the caring team, or it is anticipated that the patient will develop such needs in the very near future. These needs may be psychological, social, spiritual and/or physical. Examples may include complicated symptoms, specialist nursing needs, difficult family situations or ethical issues regarding treatment decisions
- Has been admitted to hospital acutely three or more times in the preceding 12 months
- The patient has an advanced progressive life-limiting disease
- Patient who requests discussions with specialist palliative care or Hospice team

Treatment Considerations:

- Please undertake e-consultation/advice & guidance if support is required with treatment options
- First Line Management
  - ◊ After optimising treatment of the underlying disease, the palliation of symptoms can be helped as follows:
    - Education towards self-care
    - Use of a hand held fan
    - Continue first line interventions with addition of pharmacological treatments
- Second Line Management
  - ◊ Low dose opioids: recent evidence suggesting increased risk of precipitating ventilatory failure and mortality. These disadvantages need to be balanced against the benefit in terms of management of breathlessness. The lowest effective dose should be used (a safe starting dose would usually be Morphine IR 2.5-5mg QDS)
- Third Line Management
  - ◊ Benzodiazepines are associated with increased mortality: despite this they are a reasonable 3rd line option when other treatments have failed, especially in situations where breathlessness is driven by panic/anxiety. The lowest effective dose should be used (e.g. Lorazepam 0.5mg sublingually when required)

MRC Dyspnoea Score

Grade 1) Not troubled with breathlessness except with strenuous exercise.

Grade 2) Troubled by breathlessness when hurrying on the level or walking up a slight hill.

Grade 3) Walks slower than people of the same age on the level because of breathlessness or has to stop for breath when walking at own pace on the level.

Grade 4) Stops for breath after walking about 100 yards after a few minutes on the level.

Grade 5) Too breathless to leave the house or breathless when dressing

Definitions

ADL – Activities of Daily Living

LTOT – Long term oxygen therapy

$Pa0_2$- partial pressure of oxygen

GSF- Gold Standards Framework

EOL- End of Life

EPaCCS- Electronic palliative care co-ordination systems

References:

The GSF PIG 2016 - Proactive Identification Guidance MYHT

Supportive and palliative care indicator tool (SPICT) https://www.spict.org.uk/

Chronic obstructive pulmonary disease in over 16s: diagnosis and management http://www.nice.org.uk/cg101

An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England https://www.gov.uk/government/publications/an-outcomes-strategy-for-people-with-chronic-obstructive-pulmonary-disease-copd-and-asthma-in-england

NICE COPD Quality Standards (QS 10) Published date: July 2011 Last updated: February 2016 http://guidance.nice.org.uk/QS10

Chronic obstructive pulmonary disease in over 16s: diagnosis and management July 2019 https://www.nice.org.uk/guidance/NG115

Edelman JE et al (2019) Association of prescribed opioids with increased risk of community-acquired pneumonia among patients with and without HIV., JAMA Intern Med, Jan 2019

Vozois NT, et al (2016) Increased respiratory mortality and overall mortality: - Incident opioid use and adverse respiratory outcomes among older adults with COPD.. ERJ Express July 2016

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