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Talking to Respiratory patients about death and dying

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End of Life Care Facilitator

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Agenda

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- Definitions.
- Last 12 months - How do we know?
- Trajectories of decline.
- Advance Care Planning.
- Difficult or sensitive conversations.
- Common concerns.
- Useful phases when introducing the conversation.
- Things to consider.

Definitions

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- **Terminal**

Leading towards the end*

- **Palliative**

Condition or a diagnosis of a condition that can be treated but not cured*

- **End of Life**

(based on the Gold Standard 'surprise question') someone that you would not be surprised died within the next 12 months.

*Oxford English dictionary

the gold standards framework

Last 12 months –How do we know?

- Using the ‘surprise’ question.
- Sharing and gathering information with and from other services.
- Prognostic indicators.

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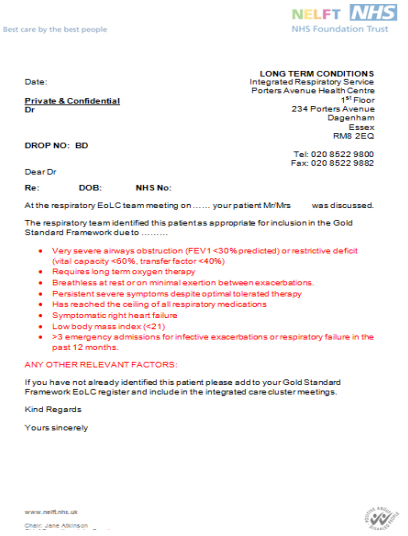

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LONG TERM CONDITIONS
Integrated Respiratory Service
Porters Avenue Health Centre
1st Floor
234 Porters Avenue
Dagenham
Essex
RM6 2EQ

Tel: 020 8522 9800
Fax: 020 8522 9882

Date:

Private & Confidential
Dr

DROP NO: BD

Dear Dr

Re: DOB: NHS No:

At the respiratory EoLC team meeting on …… your patient Mr/Mrs was discussed.

The respiratory team identified this patient as appropriate for inclusion in the Gold Standard Framework due to ……..

- Very severe airways obstruction (FEV1 <30% predicted) or restrictive deficit (vital capacity <50%, transfer factor <40%)
- Requires long term oxygen therapy
- Breathless at rest or on minimal exertion between exacerbations.
- Persistent severe symptoms despite optimal tolerated therapy
- Has reached the ceiling of all respiratory medications
- Symptomatic right heart failure
- Low body mass index (<21)
- >3 emergency admissions for infective exacerbations or respiratory failure in the past 12 months.

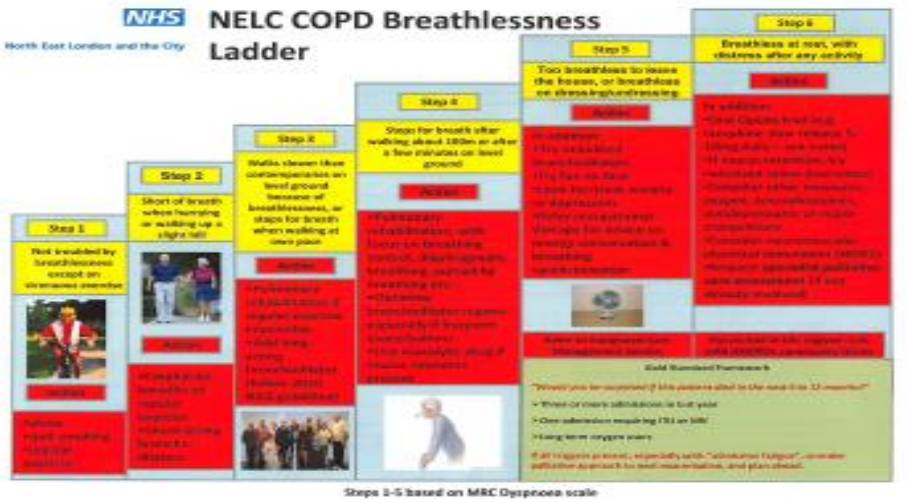
ANY OTHER RELEVANT FACTORS:

If you have not already identified this patient please add to your Gold Standard Framework EoLC register and include in the integrated care cluster meetings.

Kind Regards

Yours sincerely

www.nelft.nhs.uk
Chair: Jane Atkinson



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NHS Islington

NELFT COPD Breathlessness Guide

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Actions to be considered when you see patients between exacerbations

Step 1

Not troubled by breathlessness except on strenuous exercise

Action

Advise
- quit smoking
- regular exercise.

Step 2

Short of breath when hurrying or walking up a slight hill

Action

- Emphasise benefits of regular exercise
- Short-acting broncho-dilators

Step 3

Walks slower than contemporaries on level ground because of breathlessness, or stops for breath when walking at own pace

Action

- Pulmonary rehabilitation if regular exercise impossible
- Add long-acting bronchodilator (follow 2010 NICE guideline)

Step 4

Stops for breath after walking about 100m or after a few minutes on level ground

Action

- Pulmonary rehabilitation, with focus on breathing control, diaphragmatic breathing, pursed-lip breathing etc..
- Optimise bronchodilator regime especially if frequent exacerbations
- Use mucolytic drug if mucus retention present

Step 5

Too breathless to leave the house, or breathless on dressing/undressing

Action

In addition:
- Try nebulised bronchodilators
- Try fan on face

- Look for & treat anxiety or depression
- Refer occupational therapy for advice on energy conservation & synchronised breathing
- Consider referral to ICM teams/Community nursing teams

Step 6

Breathless at rest, with distress after any activity

Action

In addition:
- Oral Opioid trial (e.g. morphine slow release 5-10mg daily – see notes)
- If mucus retention, try nebulised saline (see notes)
- Consider other measures: *oxygen, benzodiazepines, antidepressants or major tranquillisers*
- Consider neuromuscular electrical stimulation (NMES)
- Consider referral to ICM teams /Community Nursing teams

Assess according to Gold Standard Framework

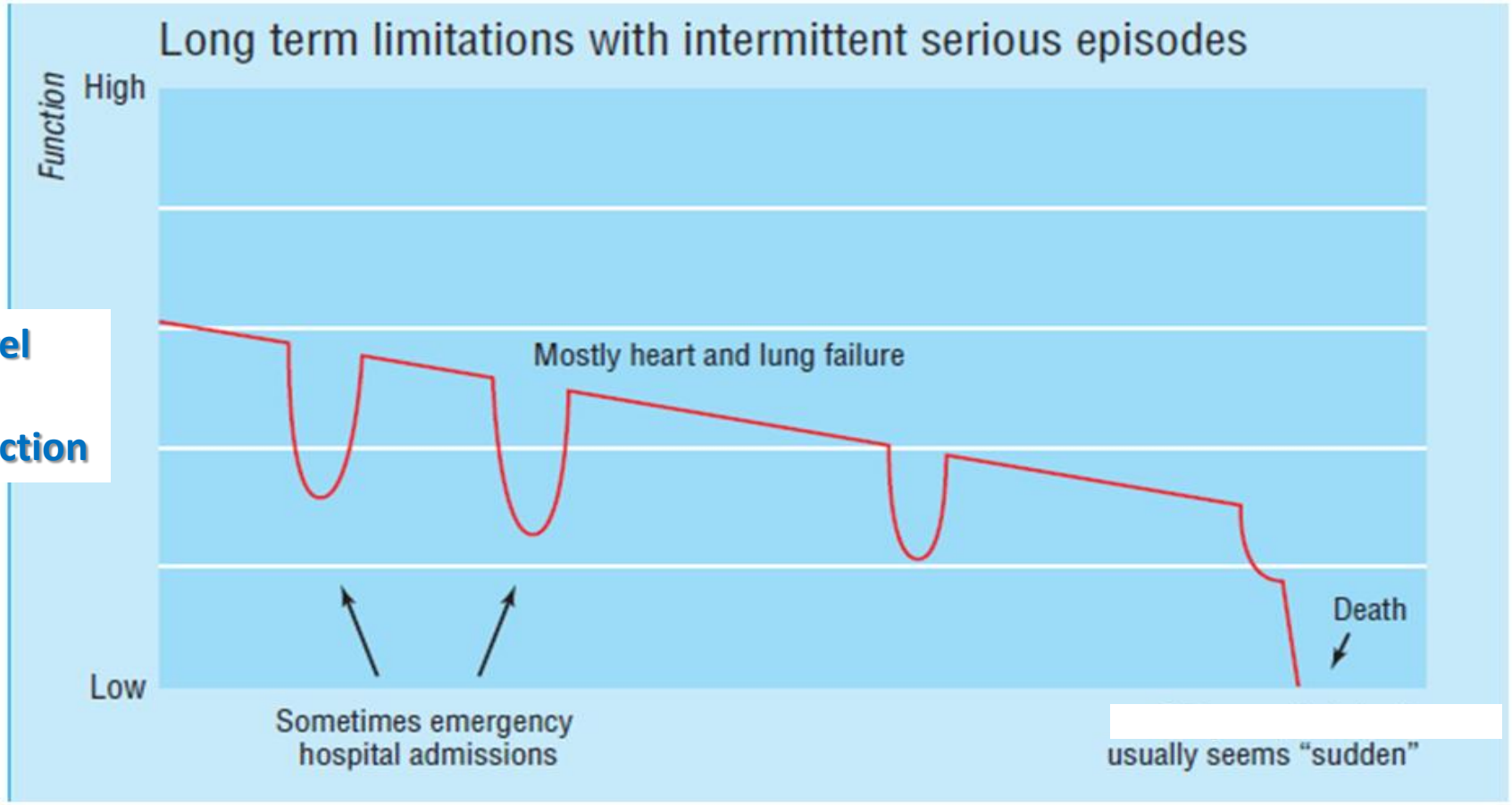
1) Three or more admissions in the last year
2) One admission requiring ITU or NIV
3) Long term oxygen users

(Also see "A QUICK GUIDE to identifying Patients for Supportive and Palliative Care")

If all 3 triggers are present, ask the "Surprise Question", Assess and consider referral to EOL services /Palliative Care services, plan ahead and where appropriate add to EOL /palliative register

Steps 1-5 based on MRC Dyspnoea scale

Trajectories of decline



Level Of function

Last 12 months of life

Advance Care Planning

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'Hope for the best
but
plan for the worst'

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Advance Care Planning

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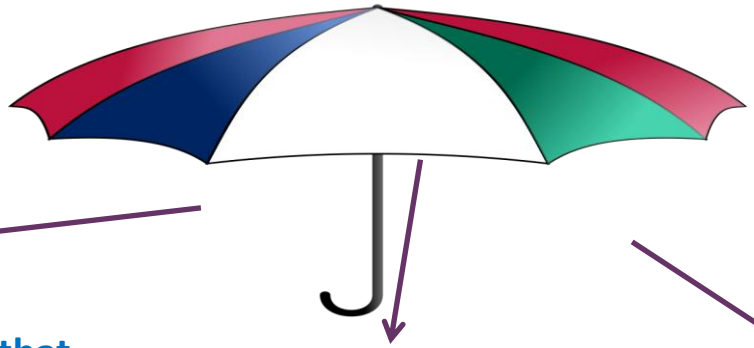

Having the discussion

*Has a patient said something that you feel may be an opportunity to discuss their future plan?

*Take opportunities as they arise rather than wait for the 'perfect time'.

*End of life care conversations can evolve over time.

*Ask the patient if they would like to record their wishes and agree to have the information shared.

Finding out their wishes, preferences or fears.

*The place they wish to be cared for and die.

*Do they want to stay at home or going into hospital, hospice or care home?

*Is there something they would not want to happen?

*Do their loved ones know of their wishes?

* Do they have family, carers or others close to them that they would like to be involved in decisions about their care?

Local Support services

*Find out what services are available

- Marie Curie,
- Macmillan,
- Local Hospice,
- Community Palliative Care Team

This varies depending on area or CCG

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Difficult or Sensitive conversations

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- Difficult for who?
- Take Opportunities as they arise rather than wait for the 'perfect' time
- Be frank but compassionate
- Take time to listen and pay attention to verbal and non verbal cues
- Avoid euphemisms and medical jargon

Common Concerns

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- Not knowing all the answers?
- Silence and tears
- Knowing the right words
- Making things worse

- It's not my role, I don't think I am the right person.
- How to start and close the conversation?

Useful phases when introducing the conversation

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- How have things been going?
- I know you have had a recent hospital admission, how was it?
- If that happened again what would you want to happen?
- What's the main thing on your mind?
- Have you got any questions about your condition and your future care?

Things to consider

- **Prognosis.** Their condition is deteriorating but how long? Be guided by the prognostic indicators
- **Acceptance.** Has your patient reached the ceiling of their medication? Should you explain that to them?
- **Investigations.** If you are not going to treat the results question why are you doing investigations?
- **Medical intervention or Comfort care?**

- **Support services** – speak with the patient and their family about services that are available and how and when they can access them.

Online resources

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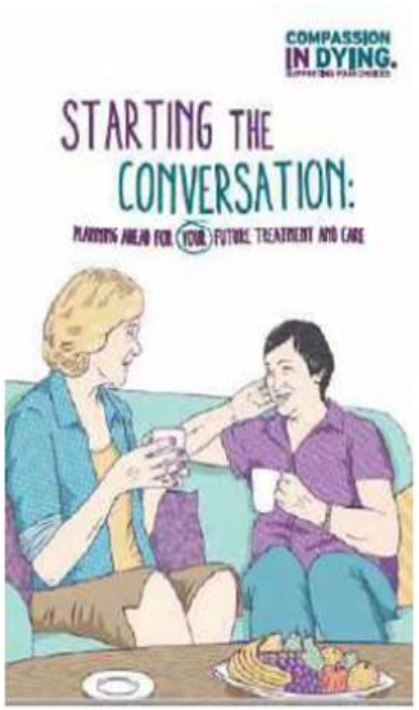

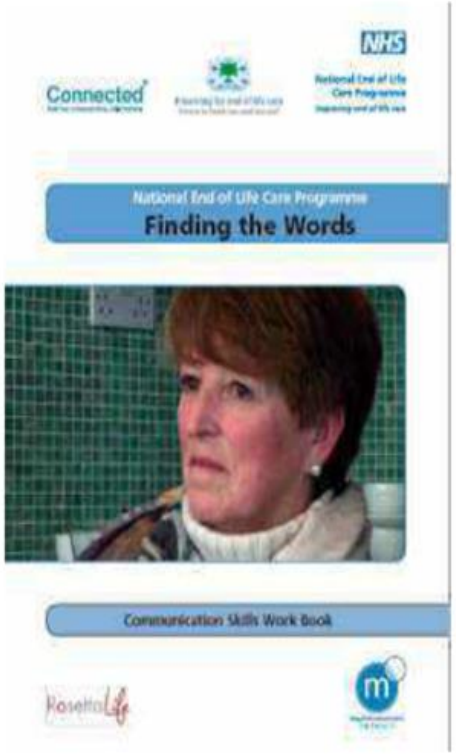

http://compassionindying.org.uk/library/starting-the-conversation/

http://www.nhsiq.nhs.uk/download.ashx?mid=8399&nid=839

http://www.dyingmatters.org/page/dying-matters-leaflets

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Thank you for listening

Any Questions?