Palliative care Non-malignant Respiratory Disease

Scott Davidson
Queen Elizabeth University Hospital
Glasgow
## UK deaths

<table>
<thead>
<tr>
<th>Place</th>
<th>All deaths (%)</th>
<th>Malignant (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>66.5</td>
<td>55.5</td>
</tr>
<tr>
<td>Hospice</td>
<td>4.3</td>
<td>16.5</td>
</tr>
<tr>
<td>Other communal</td>
<td>7.8</td>
<td>3.4</td>
</tr>
<tr>
<td>Home</td>
<td>19.0</td>
<td>23.0</td>
</tr>
<tr>
<td>Other private</td>
<td>2.4</td>
<td>1.6</td>
</tr>
</tbody>
</table>
Respiratory Management of MND patients
Introduction

• Majority of patients will die in respiratory failure
Introduction

• Respiratory muscle weakness
  – < 20% aware of symptoms at presentation
  – Develops in all as disease progresses

• Alveolar hypoventilation
  – Respiratory failure
    • Late
    • Acute
Respiratory presentations

- Breathlessness
- Orthopnoea
- Sleep disturbance
- Morning headaches
- Daytime hypersomnolence
- Ineffective cough
- Excessive secretions
- Aspiration
- Panic attacks
Respiratory presentations

• Sleep abnormalities
  – Sleep disordered breathing (17 - 76%)
    • Common SDB pattern is
      – REM sleep related hypopnoea and oxygen desaturation
      – With overall hypoventilation with more severe weakness
    • More severe patients
      – Particularly susceptible during REM when ventilation almost entirely dependant on diaphragm
Respiratory presentations

But

• Sleep disruption may be from
  • SDB
  • Orthopnoea
  • Muscle cramps
  • Difficulty managing secretions
Respiratory monitoring
Respiratory monitoring

Postal survey Neurologists 2009

- 612 referrals for NIV
- 444 successfully initiated (75%)
- 38% respondents monitored baseline function
- 20% monitored routinely
- 32% symptoms alone for referral
- 43% combination symptoms and physiology
- 26% use O2 without considering NIV 1st
NICE 2010

- 3 monthly assessment
- SpO2
  - ABG < 92% lung disease or < 94% if not
  - pCO2 > 6 immediate referral
  - pCO2 < 6 but symptoms/signs refer
- FVC/VC
- SNIP/MIP
Respiratory monitoring

VC

- > 70%
  - breathlessness unusual
- < 70%
  - Decompensation common within 12/12
- < 30%
  - Respiratory failure virtually inevitable
<table>
<thead>
<tr>
<th>Forced vital capacity (FVC) or vital capacity (VC)</th>
<th>Sniff nasal inspiratory pressure (SNIP) and/or maximal inspiratory pressure (MIP) (if both tests are performed, base the assessment on the better respiratory function reading)</th>
</tr>
</thead>
</table>
| • FVC or VC less than 50% of predicted value  
• FVC or VC less than 80% of predicted value plus any symptoms or signs of respiratory impairment (see recommendation 1.1.7), particularly orthopnoea | • SNIP or MIP less than 40 cmH\(_2\)O  
• SNIP or MIP less than 65 cmH\(_2\)O for men or 55 cmH\(_2\)O for women plus any symptoms or signs of respiratory impairment (see recommendation 1.1.7), particularly orthopnoea  
• Repeated regular tests show a rate of decrease of SNIP or MIP of more than 10 cmH\(_2\)O per 3 months |
NIV in MND
NIV in MND

Bourke et al, Lancet Neurol 2006;5:140-7

- n = 92 enrolled
- n = 41 randomised to either NIV or standard care when 1 or more of:
  - Orthopnoea
  - MIP < 60%
  - Symptomatic daytime hypercapnia
- n = 19 standard care
- n = 22 NIV
Survival

All subjects

NIV

Controls

p = 0.0062
Survival

Good bulbar function

NIV
Controls

p = 0.0059

Poor bulbar function

NIV
Controls

p = ns
Quality of Life - SF36

All subjects

Proportion surviving

Days

NIV

Controls

p=0.0017
Quality of Life - SF36

![Graph showing Good and Poor bulbar function with NIV and Controls comparisons.]

- Good bulbar function:
  - NIV
  - Controls
  - \( p = 0.001 \)

- Poor bulbar function:
  - NIV
  - Controls
  - \( p = \text{ns} \)
Quality of Life – SAQLI

All subjects

Proportion surviving

Days

NIV

Controls

p = 0.0013
Quality of Life – SAQLI

Good bulbar function

NIV Controls
p = 0.0004

Poor bulbar function

NIV Controls
p = ns

Days
Study key points

Normal or moderate bulbar
- Improved survival
  - NIV 216 days versus 11 best supportive care ($p = 0.0059$)
  - Beyond that of riluzole
- Maintenance of and improvement in QoL
  - Maintained above 75% of baseline in NIV group

Severe bulbar
- Improvement in sleep related symptoms
- Unlikely to confer large survival benefit
NIV - when to start?

- Optimum time is unclear
NIV - when to start – suggested criteria?

Any one of

• Orthopnoea with evidence respiratory muscle weakness
• Daytime hypercapnia
• ? Nocturnal desaturation
  – (SaO2 < 90% for > 5% sleep or 5 consecutive minutes)
• ? Nocturnal hypercapnia
  – (tCO2 > 6.5kPa)
NICE Guidelines 2010

- Offer to discuss the use of NIV in a timely and sensitive manner
- Include information, appropriate to the stage of illness, about:
  - possible symptoms and signs of respiratory impairment
  - natural progression of MND
  - respiratory function tests and results
  - benefits and limitations of interventions
  - how NIV can improve symptoms and prolong life
  - how NIV can be withdrawn
  - palliative strategies
- Inform relevant clinicians of key decisions agreed
<table>
<thead>
<tr>
<th></th>
<th>No Respiratory Failure</th>
<th>Respiratory Failure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n= 50)</td>
<td>All (n= 49)</td>
</tr>
<tr>
<td>Mean ± SEM</td>
<td>Mean ± SEM</td>
<td>p value</td>
</tr>
<tr>
<td>CBG (first visit)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>H+</td>
<td>37.43 ± 0.516</td>
<td>38.57 ± 0.855</td>
</tr>
<tr>
<td>pO₂ (kPa)</td>
<td>11.9 ± 0.343</td>
<td>10.5 ± 0.300</td>
</tr>
<tr>
<td>pCO₂ (kPa)</td>
<td>5.03 ± 0.093</td>
<td>6.55 ± 0.21</td>
</tr>
<tr>
<td>HCO₃</td>
<td>24.7 ± 0.480</td>
<td>31.7 ± 0.784</td>
</tr>
<tr>
<td>Progression (days)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis to first visit</td>
<td>274 ± 36</td>
<td>243 ± 55</td>
</tr>
<tr>
<td>First visit to NIV</td>
<td>X</td>
<td>59 ± 18</td>
</tr>
<tr>
<td>Diagnosis to death</td>
<td>532 ± 65</td>
<td>502 ± 48</td>
</tr>
<tr>
<td>First visit to death</td>
<td>263 ± 42</td>
<td>305 ± 45</td>
</tr>
<tr>
<td>NIV to death</td>
<td>X</td>
<td>286 ± 51</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Patients who developed Respiratory Failure during WoS LTVU follow-up, treated with NIV (n=14)</th>
<th>Patients presenting with Respiratory Failure to WoS LTVU Clinic, treated with NIV (n=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ± SEM</td>
<td>Mean ± SEM</td>
</tr>
<tr>
<td>Progression (days)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>First visit to NIV</td>
<td>160 ± 41</td>
<td>7 ± 2</td>
</tr>
<tr>
<td>Diagnosis to death</td>
<td>538 ± 100</td>
<td>536 ± 55</td>
</tr>
</tbody>
</table>
When to involve Respiratory/LTVU?

- At diagnosis
Withdrawal of NIV
Withdrawal of NIV

• Can be discontinued as a matter of choice
  – Death may be minutes to days
• Decision may be obvious concern to
  – Family
  – Healthcare professionals
  – (managers)
• Bereavement services
• Staff support mechanisms
Withdrawal of NIV

- Anticipatory Planning
Withdrawal of NIV

• Practicalities
Withdrawal of NIV

- **Who will be present?**
  - Opportunity to say goodbye essential
  - Explanation of process
  - Explanation of potential symptoms
  - Explanation of unknown timeframe

- **Who will remove the mask?**
- **Who will turn off the ventilator?**
- **Who will coordinate the process?**
Withdrawal of NIV

• Anticipatory prescribing
• Syringe driver plus bolus
  – Morphine
  – Midazolam
  – Haloperidol
  – Glycopyrronium
  – Oxygen
Withdrawal of NIV

- Bereavement and counselling
  - Withdrawal of NIV a complex emotional process
Tracheostomy ventilation
Tracheostomy ventilation

- Traditionally emergency setting
- Cuffed protects airway but
  - Swallow and speech problems
  - Immobility
  - Bronchospasm
  - Tracheomalacia
  - Haemorrhage and fistula formation
- Few long term residential facilities
- Carer burden progression to locked in
Summary

LTV involvement early with patients essential

- Respiratory monitoring
  - Symptoms
  - Physiology
  - Sleep (tosca)monitoring

- NIV complex
  - Starting
  - Optimising
  - Withdrawal

- Cough
  - To discuss in afternoon sessions
Discussion
COPD and Palliative Care

• ‘usually seems to be about letting people teeter towards the abyss in something like comfort’

John Diamond 1999
Clinical Uncertainty

- Patients managed from crisis to crisis
- Last-minute decisions about life-support
COPD versus Lung Cancer
50 COPD versus 50 Lung Cancer

COPD (FEV$_1$ < 0.75l and 1 admission type 2)
- Worse ADL
- Worse physical
- Worse social
- Worse emotional functioning
- 99% anxiety or depression (c.f. 52%)

Thorax 2000; 55: 1000-6
COPD - the last 12 months
COPD - the last 12 months

- 40% unrelieved breathlessness
- 68% unrelieved low mood
- 51% unrelieved pain
- 20% did not know ‘might’ die
- 70% died in hospital

Elkington, White et al Pall Med 2005: 19; 485 - 491
Symptom management
Symptom management

- *Palliate breathlessness (and other symptoms)*
  - COPD medication
  - Non-Pharmacological methods
  - Opiates
  - Benzodiazepines
  - Oxygen
  - Social Assessment
Symptom management

- What is breathlessness?
Symptom management

What is breathlessness?

• "subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioral responses.”

• is a symptom experienced by the individual, rather than a noticeable or measurable sign
Non-Pharmacological
Non-Pharmacological

• Information
• Fan
  – Galbraith J Pin symptom management 2010 39(5) 831-838
• Plan / Pace
  – Might include written plan for ‘attacks’ of breathlessness
• Exercise
Non-Pharmacological

• Primary
  – Determine the effectiveness of non-pharmacological and non-invasive interventions to relieve breathlessness in participants suffering from the five most common conditions causing breathlessness in advanced disease.
    • Cancer
    • COPD
    • Interstitial lung disease
    • Chronic heart failure
    • Motor neurone disease
Non-Pharmacological

Results

- 47 studies, 3532 participants
- Most studies conducted in COPD patients

- Single component interventions
  - Walking aids (7)
  - Distractive auditory stimuli (music) (6)
  - Chest wall vibration (5)
  - Acupuncture / acupressure (5)
  - Relaxation (4)
  - Neuro-electrical muscle stimulation (3)
  - Fan (2)
Non-Pharmacological

Results

- 47 studies, 3532 participants
- Most studies conducted in COPD patients

• Multi-component interventions
  - Counselling and support (5)
  - Breathing training (3)
  - Counselling and support with breathing-relaxation training (2)
  - Case management (2)
  - Psychotherapy (2)
Non-Pharmacological

Results

• High strength of evidence that NMES and CWV could relieve breathlessness.
• Moderate strength for the use of walking aids and breathing training.
• Low strength of evidence acupuncture/acupressure is helpful.
• Not enough data to judge the evidence for distractive auditory stimuli (music), relaxation, fan, counselling and support, counselling and support with breathing-relaxation training, case management and psychotherapy.

Cochrane Database Syst Review April 2008
Opiates

- To determine the effectiveness of opioid drugs in relieving the symptom of breathlessness in people with advanced disease due to malignancy, respiratory or cardiovascular disease, or receiving palliative care for any other disease.
Opiates

Results

- 26 studies, 526 participants

- Small but statistically significant positive effect when given orally or s/c

- No evidence to support nebulised route

- No evidence that they benefited exercise performance

- Only 4 studies included quality of life and none demonstrated change

Cochrane Database Syst Review March 2016
Opiates

Results

- 26 studies, 526 participants

• Adverse events (low quality evidence)
  - Drowsiness, nausea and vomiting, and constipation reported
    • 4.73 times more likely to experience nausea and vomiting compared to placebo
    • 3 times more likely to experience constipation
    • 2.86 times more likely to experience drowsiness.
Conclusions

• Low quality evidence that shows benefit for the use of oral or parenteral opioids to palliate breathlessness

• No evidence to support the use of nebulised opioids.

• Further research with larger numbers of participants, using standardised protocols and with quality of life measures included, is needed.

Cochrane Database Syst Review March 2016
Opioids – Practical advice

- Start low and increase gradually
- Start with normal release
- Img once a day increasing to 1mg twice a day
- Increase by 1mg a day each week
- Aim for 20 mg MR formulation
Benzodiazepines

• Primary objective
  – Determine the efficacy of benzodiazepines for the relief of breathlessness in people with advanced disease.

• Secondary objectives
  – Determine the efficacy of different benzodiazepines, different doses of benzodiazepines, different routes of application, adverse effects of benzodiazepines, and the efficacy in different disease groups.
Benzodiazepines

Results

• 8 studies, 214 participants
  – Cancer
  – COPD
  – MND
  – Heart Failure
  – ILD
Benzodiazepines

• Primary outcome
  – No beneficial effect of benzodiazepines for the relief of breathlessness in people with advanced cancer and COPD compared to placebo, midazolam, morphine, or promethazine.
  – No significant effect in the prevention of episodic in people with cancer compared to morphine.

Cochrane Database Syst Review Oct 2016
Benzodiazepines

• Secondary
  – No significant differences type of benzodiazepine, dose, route and frequency of delivery, duration of treatment, or type of control.
  – Benzodiazepines caused statistically significantly more adverse events, particularly drowsiness and somnolence, when compared to placebo
    • two studies reported that morphine caused more adverse events than midazolam

Cochrane Database Syst Review Oct 2016
Benzodiazepines

Conclusions

- No evidence for or against benzodiazepines for the relief of breathlessness in people with advanced cancer and COPD.
- Benzodiazepines caused more drowsiness as an adverse effect compared to placebo, but less compared to morphine.
- Benzodiazepines may be considered as a second- or third-line treatment, when opioids and non-pharmacological measures have failed to control breathlessness.

Cochrane Database Syst Review Oct 2016
Oxygen

Cochrane review

8 studies (144 patients - 97 cancer, 35 cardiac, 12 chest wall)

• No overall improvement in breathlessness, although some participants appeared to feel better
• Slight improvement in breathlessness in cardiac patients
• Review limited by small number of studies

• Individual assessment key
Oxygen – Ambulatory in COPD

• To determine the longer-term efficacy of ambulatory oxygen therapy only in patients with COPD who do not meet the criteria for LTOT, with respect to improvement in exercise capacity, mortality, quality of life and other relevant measures of improvement.

Cochrane Database Syst Review Oct 2016
Oxygen – Ambulatory in COPD

Results

– 4 studies, 331 participants

• Clinically significant benefit in favour of the intervention for dyspnoea post exercise (2 studies)
• The quality of life domain for all four included studies produced a statistically significant benefit for the subcategories of dyspnoea and fatigue, in favour of the oxygen group
• No evidence of any effect was reported for survival
• Limited benefits were observed for exercise capacity

Cochrane Database Syst Review Oct 2016
Oxygen – Ambulatory in COPD

Conclusions

• In patients with COPD with moderate hypoxia, current evidence on ambulatory oxygen therapy reveals improvements in dyspnoea post exercise and in the dyspnoea and fatigue domain of quality of life.

• However, no evidence for the clinical utility and effectiveness of ambulatory oxygen in improving mortality and exercise capacity.
Communication
GP survey in London (2005)

2/3 discuss prognosis with cancer c.f. COPD
- 73% felt this essential/often necessary
- 82% felt GP had a role in this
- 60% felt patients value discussion
- 29% felt enough info. In GP records to allow
- 50% felt time constraints a barrier
- 47% felt patients wanting to discuss do not get to

2/3 agree that prediction of prognosis difficult
Table 1. Comparison of End of Life Care by Disease.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Age Mean (Range)</th>
<th>Clinical indicators Mean</th>
<th>Admissions Mean (Range)</th>
<th>Patient Prognosis discussions (%) (n =)</th>
<th>Palliative care involvement (%) (n =)</th>
<th>Hospice referral</th>
<th>Patient wishes recorded (%) (n =)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer alone</td>
<td>18</td>
<td>72.1 (51-89)</td>
<td>2.64 (1-4)</td>
<td>1.67 (0-4)</td>
<td>80% (n = 12)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>50% (n = 7)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0</td>
<td>28.6% (n = 4)&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Chronic lung disease alone</td>
<td>12</td>
<td>74.9 (53-91)</td>
<td>3.17 (0-7)</td>
<td>4.08 (0-17)</td>
<td>33.3% (n = 4)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0</td>
<td>0</td>
<td>8.3% (n = 1)&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Frailty/stroke/dementia</td>
<td>8</td>
<td>81.8 (61-95)</td>
<td>2.63 (1-6)</td>
<td>1.63 (0-7)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lung cancer and chronic lung disease</td>
<td>8</td>
<td>72 (52-82)</td>
<td>3 (2-5)</td>
<td>3.38 (1-9)</td>
<td>87.5% (n = 7)</td>
<td>42.9% (n = 3)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>14.3% (n = 1)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>14.3% (n = 1)&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Lung cancer and frailty/stroke/dementia</td>
<td>4</td>
<td>79.3 (67-84)</td>
<td>2.25 (1-4)</td>
<td>0.25 (0-1)</td>
<td>25% (n = 1)</td>
<td>0</td>
<td>0</td>
<td>25.0% (n = 1)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Three patients with no data available.

<sup>b</sup> Four patients with no data available.

<sup>c</sup> One patient with no data available.
## Table 1. Comparison of End of Life Care by Disease.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Age Mean</th>
<th>Clinical indicators Mean</th>
<th>Admissions Mean</th>
<th>Patient Prognosis discussions</th>
<th>Palliative care involvement</th>
<th>Hospice referral</th>
<th>Patient wishes recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer alone</td>
<td>18</td>
<td>72.1 (51-89)</td>
<td>2.64 (1-4)</td>
<td>1.67 (0-4)</td>
<td>80% (n = 12)(^a)</td>
<td>50% (n = 7)(^b)</td>
<td>0</td>
<td>28.6% (n = 4)(^b)</td>
</tr>
<tr>
<td>Chronic lung disease alone</td>
<td>12</td>
<td>74.9 (53-91)</td>
<td>3.17 (0-7)</td>
<td>4.08 (0-17)</td>
<td>33.3% (n = 4)(^b)</td>
<td>0</td>
<td>0</td>
<td>8.3% (n = 1)(^b)</td>
</tr>
<tr>
<td>Frailty/stroke/dementia</td>
<td>8</td>
<td>81.8 (61-95)</td>
<td>2.63 (1-6)</td>
<td>1.63 (0-7)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lung cancer and chronic lung disease</td>
<td>8</td>
<td>72 (52-82)</td>
<td>3 (2-5)</td>
<td>3.38 (1-9)</td>
<td>87.5% (n = 7)</td>
<td>42.9% (n = 3)(^c)</td>
<td>14.3% (n = 1)(^c)</td>
<td>14.3% (n = 1)(^c)</td>
</tr>
<tr>
<td>Lung cancer and frailty/stroke/dementia</td>
<td>4</td>
<td>79.3 (67-84)</td>
<td>2.25 (1-4)</td>
<td>0.25 (0-1)</td>
<td>25% (n = 1)</td>
<td>0</td>
<td>0</td>
<td>25% (n = 1)</td>
</tr>
</tbody>
</table>

\(^a\) Three patients with no data available.

\(^b\) Four patients with no data available.

\(^c\) One patient with no data available.
## Table 1. Comparison of End of Life Care by Disease.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Age Mean (Range)</th>
<th>Clinical indicators Mean (Range)</th>
<th>Admissions Mean (Range)</th>
<th>Patient Prognosis discussions (%) (n =)</th>
<th>Palliative care involvement (%) (n =)</th>
<th>Hospice referral (%)</th>
<th>Patient wishes recorded (%) (n =)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer alone</td>
<td>18</td>
<td>72.1 (51-89)</td>
<td>2.64 (1-4)</td>
<td>1.67 (0-4)</td>
<td>80% (n = 12)</td>
<td>50% (n = 7)</td>
<td>0</td>
<td>28.6% (n = 4)</td>
</tr>
<tr>
<td>Chronic lung disease alone</td>
<td>12</td>
<td>74.9 (53-91)</td>
<td>3.17 (0-7)</td>
<td>4.08 (0-17)</td>
<td>33.3% (n = 4)</td>
<td>0</td>
<td>0</td>
<td>8.3% (n = 1)</td>
</tr>
<tr>
<td>Frailty/stroke/dementia</td>
<td>8</td>
<td>81.8 (61-95)</td>
<td>2.63 (1-6)</td>
<td>1.63 (0-7)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lung cancer and chronic lung disease</td>
<td>8</td>
<td>72 (52-82)</td>
<td>3 (2-5)</td>
<td>3.38 (1-9)</td>
<td>87.5% (n = 7)</td>
<td>42.9% (n = 3)</td>
<td>14.3% (n = 1)</td>
<td>14.3% (n = 1)</td>
</tr>
<tr>
<td>Lung cancer and frailty/stroke/dementia</td>
<td>4</td>
<td>79.3 (67-84)</td>
<td>2.25 (1-4)</td>
<td>0.25 (0-1)</td>
<td>25% (n = 1)</td>
<td>0</td>
<td>0</td>
<td>25.3% (n = 1)</td>
</tr>
</tbody>
</table>

* a Three patients with no data available.
* b Four patients with no data available.
* c One patient with no data available.
# Table 1. Comparison of End of Life Care by Disease.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Age Mean</th>
<th>Clinical indicators Mean</th>
<th>Admissions Mean</th>
<th>Patient Prognosis discussions</th>
<th>Palliative care involvement</th>
<th>Hospice referral</th>
<th>Patient wishes recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer alone</td>
<td>18</td>
<td>72.1 (51-89)</td>
<td>2.64 (1-4)</td>
<td>1.67 (0-4)</td>
<td>80% (n = 12)^a</td>
<td>50% (n = 7)^b</td>
<td>0</td>
<td>28.6% (n = 4)^b</td>
</tr>
<tr>
<td>Chronic lung disease alone</td>
<td>12</td>
<td>74.9 (53-91)</td>
<td>3.17 (0-7)</td>
<td>4.08 (0-17)</td>
<td>33.3% (n = 4)</td>
<td>0</td>
<td>0</td>
<td>8.3% (n = 1)</td>
</tr>
<tr>
<td>Frailty/stroke/dementia</td>
<td>8</td>
<td>81.8 (61-95)</td>
<td>2.63 (1-6)</td>
<td>1.63 (0-7)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lung cancer and chronic lung disease</td>
<td>8</td>
<td>72 (52-82)</td>
<td>3 (2-5)</td>
<td>3.38 (1-9)</td>
<td>87.5% (n = 7)</td>
<td>42.9% (n = 3)^c</td>
<td>14.3% (n = 1)^c</td>
<td>14.3% (n = 1)^c</td>
</tr>
<tr>
<td>Lung cancer and frailty/stroke/dementia</td>
<td>4</td>
<td>79.3 (67-84)</td>
<td>2.25 (1-4)</td>
<td>0.25 (0-1)</td>
<td>25% (n = 1)</td>
<td>0</td>
<td>0</td>
<td>25% (n = 1)</td>
</tr>
</tbody>
</table>

^a Three patients with no data available.

^b Four patients with no data available.

^c One patient with no data available.
**Respiratory Unit GG&C**

### Table 1. Comparison of End of Life Care by Disease.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Age Mean (Range)</th>
<th>Clinical indicators Mean</th>
<th>Admissions Mean</th>
<th>Patient Prognosis discussions</th>
<th>Palliative care involvement</th>
<th>Hospice referral</th>
<th>Patient wishes recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer alone</td>
<td>18</td>
<td>72.1 (51-89)</td>
<td>2.64 (1-4)</td>
<td>1.67 (0-4)</td>
<td>80% (n = 12)</td>
<td>50% (n = 7)</td>
<td>0</td>
<td>28.6% (n = 4)</td>
</tr>
<tr>
<td>Chronic lung disease alone</td>
<td>12</td>
<td>74.9 (53-91)</td>
<td>3.17 (0-7)</td>
<td>4.08 (0-17)</td>
<td>33.3% (n = 4)</td>
<td>0</td>
<td>0</td>
<td>8.3% (n = 1)</td>
</tr>
<tr>
<td>Frailty/stroke/dementia</td>
<td>8</td>
<td>81.8 (61-95)</td>
<td>2.63 (1-6)</td>
<td>1.63 (0-7)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lung cancer and chronic lung disease</td>
<td>8</td>
<td>72 (52-82)</td>
<td>3 (2-5)</td>
<td>3.38 (1-9)</td>
<td>87.5% (n = 7)</td>
<td>42.9% (n = 3)</td>
<td>14.3% (n = 1)</td>
<td>14.3% (n = 1)</td>
</tr>
<tr>
<td>Lung cancer and frailty/stroke/dementia</td>
<td>4</td>
<td>79.3 (67-84)</td>
<td>2.25 (1-4)</td>
<td>0.25 (0-1)</td>
<td>25% (n = 1)</td>
<td>0</td>
<td>0</td>
<td>25% (n = 1)</td>
</tr>
</tbody>
</table>

*a* Three patients with no data available.

*b* Four patients with no data available.

*c* One patient with no data available.
COPD patient held record pilot

- Section 4 – Anticipatory care Plan

**Section 4: Anticipatory Care Plan (2 pages)**

- Completed by the doctor or nurse along with yourself and updated at each visit if necessary.

**Patient Details:**

- Date completed:

**What is wrong?**

- This should include a description of the medical condition and how it is being managed. It should also include the patient’s perception of what is wrong.

**What has changed?**

- This should include a description of how the patient’s medical condition has changed and to what degree, and also the patient’s perception of any change.

**How are these changes being managed?**

**Patient Preferences and Priorities**

- This should summarise the treatment plan in the event of further deterioration, including alternative care options.

**Summary of discussion with patient / family / carer regarding care plan as detailed above.**

**Patient Details:**

- Date completed:

- Patient agrees with Plan and consents to share it with others: Yes ☐ No ☐ N/A

- Family / Carer aware of Plan: Yes ☐ No ☐ N/A

- Anticipatory Care Plan shared with Out of Hours: Yes ☐ No ☐ N/A

- On Palliative Care / Intensive Care Management Register: Yes ☐ No ☐ N/A

- Do Not Attempt Resuscitation (DNACPR) form completed: Yes ☐ No ☐ N/A

- Adults with Incapacity Scotland (Scotland) Act completed: Yes ☐ No ☐ N/A

- Date of Review: __________

- Next Review date: __________

- Signature: __________

- Designation: __________

- Print name: GP / Consultant aware of review: Yes ☐ No ☐

- Patient signature: __________

- Date: __________

**Copy of Plan for Future Summary sent / faxed to**

- GP Name: __________ Date sent: __ / __ / __

- DN Name: __________ Date sent: __ / __

- Respiratory CNS: __________ Date sent: __ / __

- Consultant: __________ Date sent: __ / __ / __
COPD patient held record pilot

Feedback

• ‘Patient Held Document – a good idea’
• ‘Regular visits very beneficial’
• ‘Feel safer at home’
• ‘Good to complete the document with the Respiratory Nurse Specialist’
• ‘Didn’t think to share it with other health care professionals’
COPD patient held record pilot

• “I feel much safer knowing that the respiratory nurse is coming out to see me regularly. I feel the care is more personal, more about me, and I know that if I have any problems I can just lift the phone and ask the nurse’s advice … I know the nurse is there for me…. And… I know that she sees my Consultant as well…. so that reassures me because I can no longer get to see him.” (Patient B)
COPD patient held record pilot

• ‘I am not just left to cope on my own now that I’m not going to the clinic. I know there’s someone there to listen and to help me’ (Patient F)
COPD patient held record pilot

- I think it’s good … because it means that I know her condition is being monitored….she’s not just being forgotten about. She wants to be at home and I want to look after her at home because we’ve been together for forty years….. so its good to have that support… good to have that contact with the respiratory nurse…I feel safer and she feels safer….” (The carer of patient G)
• “I have read it all ... but I should make sure my son and daughter read it .. especially my daughter ... as I don’t think she really realises what this illness is about. See my mother died of COPD and I’m a lot worse than my mother was. I don’t think they realise...”  (Patient C)
COPD patient held record pilot

• “Putting it on paper helped me… and it has helped my family… my husband has found it difficult to cope with … but… I can tell my son and the document has helped me do that … I know that they know what I want.. there can be no misunderstandings.” (Patient F)
Questions