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Evidence Based Scan for My Health My Community (MHMC)

Pennine Care NHS Foundation Trust

Caring for someone with COPD at the end-of-life

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Executive summary

This Evidence Base Scan (EBS) examines the main issues and concerns for Chronic Obstructive Pulmonary Disease (COPD) patients and carers which requires long term support. Family centred support appears to be very necessary for this group given the length of time they may be involved in supporting and caring for a COPD patient and some of this is identified below. There is a focus on managing COPD with pulmonary rehabilitation and/or palliative and end-of-life care because, as a disease with an uncertain trajectory, it is often unclear to lay and professionals when supportive and/or palliative care should shift towards end-of-life care. This scan offers an introduction to issues with COPD including difficulty with prognosis and work being undertaken to resolve these issues. The carer experience and burden of the COPD trajectory is described with resources available to alleviate this, with the focus then moving towards carer needs in advanced disease which pivot around palliative care, pulmonary rehabilitation and end-of-life and Advanced Care Planning.

Specific issues in COPD, particularly breathlessness are dealt with in depth and there are some excellent resources for PCFT to draw upon which are described in detail. Linked issues are also covered relating to breathless and its palliation. Additional end-of-life issues are identified and addressed including depression and COPD self management and carer support interventions are described. For carers, bereavement information and support as part of end-of-life care provision had been highlighted as an area of concern. No model of provision currently exists for bereaved relatives of people with COPD who may have been long term carers (COPD Strategy Document).

Training for HCPs covers Advanced Care Planning and end-of-life conversations and COPD end-of-life and management pathways are also described. UK and some International good practice in COPD care is offered.

The final section covers general end-of-life care. Some of this information is in previous EBSs but there are some new resources added in and its presence herein allows this document to stand alone as a resource for COPD.

Please note that this document is best read in conjunction with “Education and support for Carers of People at the End of Life”.

Part 1: Section 1

This EBS will focus on end-of-life (EoL) care for patients and carers of people with Chronic Obstructive Pulmonary Disease (COPD). It will examine what life is like for COPD patients and carers and what their main issues and concerns are through the disease trajectory particularly at the EoL. It will identify and describe support and training for carers in order to help them undertake this role.

COPD describes a number of conditions including emphysema and chronic bronchitis. COPD describes lung damage that is gradual in onset and results in progressive airflow limitation. When fully established, this lung damage is irreversible, leading to disability and eventually death if it is not identified and treated early (Department of Health, 2011).

COPD is a major cause of morbidity, disability and mortality worldwide (Figueiredo, et al, 2014) having a global prevalence of around 10% in those aged over 40 years (Figueiredo, et al, 2014). The Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2013)[1] criterion for COPD classifies the disease in stages I–IV (mild, moderate, severe and very severe) according to the value of FEV1 as a percentage of the predicted value (Sunde, et al 2014).

By 2030, COPD is predicted to have become the third-leading cause of death worldwide, with 90% of those deaths occurring in low and middle income countries. Approximately 1.5 million people in the UK are affected by COPD with over 27,000 deaths in the UK in 2004 being due to the disease (Figueiredo, et al, 2014), nearly as many as lung cancer deaths and with similar health and social care needs (White, et al, 2011). Given its gradual course and the older age of patients, COPD is frequently underdiagnosed and undertreated (Figueiredo, et al, 2014), many people not receiving a diagnosis until they are over 50; the average age of death from COPD being 76. The COPD prognosis is poor and associated with a high symptom burden/symptom distress, impaired functional status (Gardiner et al, 2013) and psychological and social morbidity. The experience of this illness has an impact beyond the patient (Philip et al, 2014) and represents a significant burden for families (Figueiredo, et al, 2014).

COPD results in progressive, non-variable symptoms. Patients do not have symptom free days and these worsen during exacerbations[2] which occur throughout the disease trajectory. These may require hospitalisation and consideration of assisted ventilation. Symptoms experienced by people living with COPD include, breathlessness, fatigue, lack of mobility, sleep disturbance, sputum production, uncontrolled coughing and

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[1] *Global Initiative for chronic obstructive lung disease. Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease (updated 2015).*

[2] *Exacerbation - "an event in the natural course of the disease characterized by a change in the patient's baseline dyspnoea, cough and/ or sputum that is beyond normal day-to-day variations, is acute in onset and may warrant a change in medication in a patient with underlying COPD" cited in (GOLD, 2013, p40)*

pain. Everyday living is restricted because of physical constraints caused by the disease and because patients fear their symptoms may worsen. Patients can suffer significant anxiety and depression and gradually become more dependent on significant others (Figueiredo, et al, 2014: Horton et al, 2013). In the advanced stages of COPD, symptoms are often worse than those in advanced lung cancer, (Horton et al, 2013). Additional comorbidities can include ischaemic heart disease, arthritis, mental illness, diabetes and stroke, although these do not appear to affect the degree of severity of breathlessness or lung function (White, et al, 2011).

COPD illustrates the ‘organ failure’ EoL trajectory in which a gradual decline is punctuated by acute severe exacerbations, any one of which may be fatal. A patient may survive the majority of these exacerbations, but because it is unclear which exacerbation will be fatal, death may seem to occur suddenly (Duenke, et al, 2014). Quality of life in the terminal phase is, very often, poor (Booker, 2010). A steady downward decline is replaced with a relatively unpredictable series of stable periods dispersed with troughs. The troughs represent an acute exacerbation AECOPD[3] (attack of breathlessness) from which the patient may recover back to a relatively good degree of health (Reinke, et al, 2011). However, frequent exacerbations lead to increased mortality, with a 5-year survival rate of 40–50% (Sunde, et al 2014), final years being characterised by progressive deterioration in function and quality of life and incapacitating breathlessness, many patients and their caregivers failing to realise that COPD is life-threatening and may need palliative and/or EoL care (Horton, et al, 2013).

1.1 COPD care in the North West of England

The state of play in the North West at the moment is encapsulated in an excellent report from AQuA which can be accessed from https://www.aquanw.nhs.uk/resources/copd-care-in-the-north-west-of-england/20796. Some of the information in various sections of this EBS is sourced from here. The introduction below offers a flavour of what this document can offer PCFT.

1.2Introduction

This report seeks to highlight the areas where further improvements in the quality of COPD services might be beneficial to patients, and to place them alongside the areas where the care is already good and excellent. Ten areas have been identified which appear to offer the greatest opportunity to further improve COPD services and outcomes across the North West of England.

AQuA’s benchmarking compares Commissioners in the North West to both the North West and England as a whole. We hope this report will stimulate thought and debate within organisations and health communities. Further benchmarked data and improvement advice can be found in AQuA’s COPD Improving Outcomes Pack. This can be found on the AQuA Portal (For access contact anthony.mather@srft.nhs.uk).

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[3] *An AECOPD being defined as an acute worsening* of the patient’s condition from the stable state, which is sustained and may warrant the patient seeking additional treatment (Duenke, et al, 2014).

1.3 Methods

This EBS is pragmatic and uses some of the principles of ‘evidence scans’ as described by the Health Foundation. This approach provides information to help those involved in improving the quality of healthcare to understand what research is available on particular topics. The purpose is to provide a synopsis of evidence to help inform discussions and to help identify if there is need for further research or development in the area covered. It can also provide a rapid collation of empirical research about a topic. Although all of the evidence is sourced and compiled systematically, this is not classed as a systematic review. That is, it does not seek to summarise theoretical literature or to explore in any depth the concepts covered by the scan or those arising from it. Elements of 'Berry picking' were also used. This is another structured method of searching which also allows for an iterative and creative searching process to take place such as citation searching, reference and author chasing. The whole process involved:

- Meetings and communications with stakeholders
- A Google grey literature search for any education programmes/initiatives (this included health provider sites and websites with a target audience of patients/carers coping with terminal illness, advanced illness and End of Life issues.)
- An examination of related websites, reports, conference presentations and academic papers
- Personal communications with programme leads and/or researchers
- A Manchester Library academic search
- An appraisal of existing programmes and initiatives
- Recommendations for practice

Table 1 summarises the academic search criteria. The search included papers from 2010-2015 in the English language. The time period of five years was decided upon because of the complexity of COPD, its potentially lengthy trajectory and co-morbidities and the time constraints for the completion of the EBS. English language articles were selected. Newspaper articles, books or primarily clinically focused papers were excluded. Additional papers were identified from previous phases, a citation search and following another search before finalising this document.

The searches for these EBS differ from traditional reviews because the nature of the information PCFT is requesting necessitates a pragmatic, practical approach to identifying and reviewing the evidence base. A practical resource was requested with an evidence base to support this, thus rather than the traditional academic search, the best place to begin was a general Google search followed by a Google Scholar search[4].

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[4] There is evidence that Google Scholar consistently achieves higher retrieval rates than other search engines (Caching, 2010).

This was then reinforced by the University of Manchester (UoM) search to ensure that it was evidence based (databases included in this search are here[5]). Talking to researchers and/or authors of papers, attending lectures and talks and chasing references and citations also rendered much information.

Table 1. Search Criterion

Sources	**Terms**
University of Manchester search Google scholar search Citation and reference searching Google search Author searching COPD specific websites	COPD and……
	'End of life care' *'End stage'* *'Advanced'* *'Severe'* *'Home care'* *'Family carer'* *'Carer education'* *'Carer Burden'* *'Symptoms and End of Life Care'* *'End of life care and comorbidities'* *'End of life care and lay carers'* *'End of life care and family carers'*

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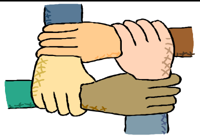
[5] This search covered; Taylor & Francis Online – Journals, SpringerLink Open Access SpringerLink SciVerse ScienceDirect (Elsevier) SAGE Journals Public Information Online (Dandy Booksellers) PMC (PuBAMEd Central) Oxford Journals (Oxford University Press) MEDLINE/PuBAMEd (NLM) Literature Resource Center (Gale) C.E.E.O.L Journals Karger Journals IngentaConnect Emerald Journals (Emerald Group Publishing) Duke University Press Journals Online Directory of Open Access Journals (DOAJ) Cambridge Journals (Cambridge University Press) BioMed Central ACM Digital Library ERIC

1.4 Flag system for appraising evidence

☀	**VERY RELEVANT TO PCFT** Worth contacting this initiative
✡ ✡	**DENOTES VERY GOOD PRACTICE** This could mean that the programme/guideline/initiative: • Is established practice • Has been nominated for an award • Has won an award • Is a completed successful pilot • Is part of a larger programme • Is the subject of a peer reviewed paper • Meets a number of important guidelines
✡	**DENOTES GOOD PRACTICE** This could mean that the programme/guideline/initiative: • could have been funded
📜	**ENDORSED, RECOMMENDED BY…**

	**PILOT STUDY**
	**A CO-DESIGNED INITIATIVE** with lay and professionals
	**COMPLETED INITIATIVE**
	**ONGOING INITIATIVE**
	**HAS A BAME/LGBT COMPONENT**

In addition, recommendations in red boxes are also red flag recommendations for Pennine Care NHS Foudnation Trust.

1.5 Prognostic indicators

"Well, end stage is from the beginning, isn't it, to a certain extent?" (Pinnock, et al, 2011)

Prognosis in COPD is difficult and death often occurs 'before the patient is perceived as being *terminal*'. Many patients die 'with', rather than 'of' COPD, and causes of death include respiratory (35%), cardiovascular (26%), cancer (21%) and other causes (18%) (Momen, et al, 2012).

The policy focus on identifying a time point for transition to palliative care is difficult to apply to people with COPD, their carers or doctors given its uncertain trajectory. It could be counter-productive if it distracted from an early phased introduction of supportive care. Therefore, careful assessment of possible supportive and palliative care needs should be triggered at key disease milestones along the trajectory of COPD (Pinnock, et al, 2011).

Meanwhile, professional homecare can include several aspects such as home visits, telephone calls, education, and support in acquiring and applying self-management skills. Home visits by a nurse, combined with the availability of a nurse specialist by phone, have been shown to reduce symptoms of depression in patients with COPD. Patients and their informal caregivers need care that is coordinated within and between care settings, by a person who is empathic and cooperative (Nakken, et al, 2015).

Few COPD patients talk about their EoL care even though they know it is life limiting (White, et al, 2011). Each subsequent admission to the hospital for an acute exacerbation of COPD, therefore, also creates an opportunity to initiate discussions around the need for EoL conversations, Advanced Care Planning (ACP) and Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decision-making (Duenke, et al, 2014). These will be discussed below.

Determining end-stage COPD is difficult and although clinicians have a variety of indices which can enhance their ability to predict mortality, lung function being a strong predictor, other elements of the disease need to be taken into account. As COPD severity increases, deaths due to respiratory disease are increasingly common. The presence of comorbid disease increases the risk of both hospitalisation and mortality[6]. There is no evidence to support the making of a prognosis of less than 2 years in individuals with advanced COPD, irrespective of respiratory disease severity. The section below describes a completed prognostic indicator, COPD-CART, and one in development, PROLONG. A later section, "Good Practice" (page, 25) describes a major NHS project which addresses key issues in COPD care including prognostic indicators.

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[6] *These will not be covered in this scan. There is an EBS, "Stroke and End of Life care" however*.

1.6 Completed prognostic indicators

1.6.1 BODE

The best current prognostic model is the BODE Index, (Puhan, et al 2009) which is better at predicting death than forced expiratory volume in 1 (FEV1) alone. As with all such models, this is of some use with groups of patients but of little help with individuals (Momen, et al, 2012). However, BODE was established in 2009 and the indicators below have built upon this measure subsequently.

1.6.2 COPD-CART

A validated decision tree has been developed which uses variables commonly gathered by doctors (age, % predicted forced expiratory volume in 1 s (FEV1), dyspnoea, physical activity, general health and number of hospital admissions for COPD exacerbations in the previous 2 years) and which provides a quick assessment of the severity of the disease, as measured by the risk of 5-year mortality. Such a decision tree may help physicians estimate prognoses for their COPD patients and potentially influence clinical decision making.

It has a robust basis in terms of predictors of mortality and compared with previous measures (the BODE index, the new BODEx index and the HADO score (Esteban, et al, 2006), it is simple to use. Doctors follow the branches relevant to the patient under study. It provides a global vision not only of what can be expected for a particular patient but also what can be expected if the patient’s status changes.

The ability of the COPD-CART to predict mortality is similar to that of previous measures appearing to have a better prognostic ability. Because it was tested on a large number of patients, additional variables were included which affect mortality in some cases.

The utility of a clinical decision rule that is easily applied in daily practice is extremely useful. A decision tree mirrors how doctors think about prognosis on a day to day level. This tool can easily establish a prognosis without doctors needing to memorise scores of other variables. The COPD-CART decision tree employs measures generally gathered by physicians in the evaluation of COPD patients, provides a quick assessment of the severity of the disease, as measured by the risk of premature death and by patient-perceived health related quality of life.

The ability of the COPD-CART to predict 5-year mortality is as good as, or better than, that of other existing indices, but is easier to use in routine clinical practice. Although well validated in this study, (being derived in a cohort of 611 patients and validated with 348 patients) the COPD-CART still needs to be tested in various other settings, with other populations and measures before it can become widely used (Esteban, et al, 2011).

1.6.3 PROLONG

Duenke, et al, 2014 are assessing, through a cluster controlled trial. the “PROLONG” study, the discriminating power of a set of indicators developed to identify in patients hospitalised for acute exacerbation who are at risk for post discharge mortality. It is only after these issues have been identified that a multi-disciplinary team approach to proactive palliative care for COPD patients can be initiated. Barriers to proactive palliative care for COPD patients prevent this from being common practice for them.

The objectives of the PROLONG study are:

- to assess the discriminating power of the proposed set of indicators. (The primary outcome measure being time to death for any cause).
- to assess the effects of proactive palliative care for qualifying patients with COPD on the wellbeing of these patients and their informal caregivers. (The primary outcome measure is the change in quality of life measured by the St George Respiratory Questionnaire (SGRQ) three months after inclusion).

The study hypothesis is that the set of indicators can predict readmission within 8 weeks and/or death within 1 year for patients hospitalised for an acute exacerbation of COPD. The PROLONG study may lead to better understanding of the conditions to start palliative care, and the effectiveness of proactive palliative care for patients with COPD. Innovative aspects of the PROLONG study are the use of a set of indicators for proactive palliative care, the active involvement of a specialised palliative care team and the use of a patient-tailored proactive palliative care plan[7] (Duenke, et al, 2014).

1.7 Prognostic indicators in progress

1.7.1 BOD A prognostic indicator for COPD?

Improving identification of EoL care needs and ACP to support preferred place of care for patients with COPD. Hartlepool PCT

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[7] *Trial registration: Netherlands Trial Register (NTR): NTR4037*

The respiratory nursing care community team already have a well-established service which operates out of the heart of Hartlepool in new facilities – 'One Life'.

The current team also have a well-established link to the palliative care community team as part of their commitment to develop effective and quality care pathways for patients, they wanted to address the particular challenges of the EoL pathway in COPD.

A multidisciplinary EoL group adapted an existing set of indicators including: body mass index, FEV1 obstruction and MRC dyspnoea score (originally including exercise and known as BODE – The BODE index predicted death in chronic obstructive pulmonary disease[8] which subsequently became known as "BOD" in this context and which they trialled.

Aims and objectives:

To improve recognition of the deteriorating COPD patient and their end stage/EoL potential by utilising the "BOD" tool as a prognostic indicator and trigger to facilitate EoL discussion and referral to resources.

Process:

- Baseline data was collected on the number of patients on the COPD registers.
- The BOD index was then used to identify patients on the COPD register who were eligible for discussion around their condition and given the opportunity for ACP.
- The implementation of BOD in primary care
- A process of staff awareness raising and training on BOD as a prognostic indicator tool and EoL care discussions took place alongside the case finding.
- To date five practices are routinely recording BOD scores during routine COPD patient reviews. Scores are recorded on a template and any increase in score at future consultations will indicate a deteriorating patient.

Issues and challenges

- More practices are needed to agree to record the BOD index in order to demonstrate an evidence based benefit
- Implementation is considered part of an on-going plan to improve shared decision making, autonomy and access to resources for COPD patients.

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[8] Celli BR, Cote CG, Marin JM, et al. The body-mass index, airflow obstruction, dyspnoea, and exercise capacity index in chronic obstructive pulmonary disease. N Engl J Med 2004;350:1005–12.

Once staff are familiar with the BOD philosophy, and develop practice based templates for recording BOD scores, they should be able to implement this with support.

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1.8 Improving EoL care in COPD: testing the case for change. NHS Improvement Lung National Improvement Projects (2011)

This project addresses key issues in COPD care, prognostic indication, ACP and palliative care. All the projects within this work stream have been building the evidence for the creation of a gold standard pathway for COPD EoL patients. Key learning is centred on the following themes:

Prognostic indicators – Sites were testing two different indicators; the Gold Standards Framework Indicators and the BOD (Body Mass Index, Obstruction, Dyspnoea score), because evidence was indicating that there was variability in the reliability and validity of using indicators to accurately predict the last 6 to 12 months of life.

Advance Care Planning – Giving people the opportunity to discuss their wishes around issues such as, resuscitation and representation on loss of capacity is important and should be undertaken when the patient is as well as possible.

Raising awareness – The issue of death and dying is a sensitive topic, but lack of awareness amongst patients and more surprisingly amongst staff, about the potentially life threatening nature of the condition impacts on the care COPD patients receive in the final stages of life. The tendency to continue with proactive management of symptoms and maintain a positive prognosis means seriously ill patients are at risk of not being able to plan ahead at the right time with full understanding of their condition.

End of life registers – Currently, palliative care Quality Outcomes Framework (QOF) registers are utilised in GP practices to identify those people approaching the end of life, thereby helping ensure that their needs are met. However, they are generally biased towards the care of those with cancer.

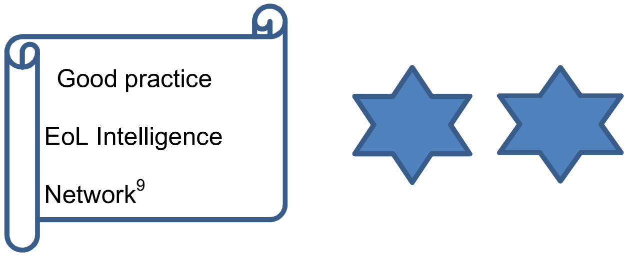
The three projects comprise:

1a. “BOD” A prognostic indicator for COPD? Improving identification of End of life Care needs and ACP to support preferred place of care for patients with COPD. *Hartlepool PCT*. (page 19)

1b. “Breathing Space”: Prognostic indicators and advance care planning in COPD *Rotherham Foundation NHS Trust*. (see page 23)

1c. Improving identification of EoL care needs and ACP to support preferred place of care for patients with COPD. *Solihull Community NHS Care Trust*, (see page 91)

1.9 Breathing Space: Prognostic indicators and advance care planning in COPD. Rotherham Foundation NHS Trust



Breathing Space[10] is a unique nurse led facility, being the largest multidisciplinary community based COPD rehabilitation programme in Europe. It has been identified that many of the COPD patients at Breathing Space had at least one of the Gold Standards Framework prognostic (PIG) indicators[11] often used to determine the last 12 to 6 months of life. This provided the catalyst for the service to look at the provision of EoL care and how this part of the pathway could be improved.

The project aims and objectives are:

- To advance the service delivery model for EoL care at Breathing Space as a choice for COPD patients and to support the carers of these patients.

Project questions:

- Are Gold Standards Framework prognostic indicators for COPD predicting death within 12 months?
- Are COPD patients with at least one Gold Standards Framework prognostic indicator - and their carers - interested in participating in ACP?
- Do staff feel that patients with at least one Gold Standards Framework prognostic indicator are appropriate to be approached for ACP?
- Do patients who have had ACP achieve their preferred place of care and other goals?
- Do senior staff feel competent and confident at having these discussions after appropriate training?

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[9] *See; Deaths from Respiratory Diseases: Implications for end of life care in England (2011) ISBN: 978-0-9569225-1-9 www.endoflifecare-intelligence.org.u*

[10] *From 2011, Breathing Space was amalgamated with Rotherham Foundation NHS Trust*

[11] *GSF (2011). "The GSF Prognostic Indicator Guidance." (PIG)*

Process:

A baseline audit was undertaken to determine whether there was any evidence to suggest prognostic indicators would be found amongst previous patients who were admitted to Breathing Space. This revealed 60% already had at least one PIG.

An audit was then undertaken to capture any prognostic indicators present in patients attending assessment as an outpatient to the pulmonary rehabilitation programme and at time of admission during an acute exacerbation. This asked the staff member responsible for admission to decide whether to initiate an ACP discussion[12] with the patient.

Breathing Space found that one prognostic indicator was not necessarily an appropriate prompt for initiating this kind of discussion. Staff were then asked to use three indicators as a trigger point, or not, for such a discussion. Following a base line audit of staff training skills, ten staff on the inpatient unit attended a preliminary training session on advanced communication skills delivered by a palliative care specialist.

Findings:

Many staff indicated that they felt a certain level of unease when asked to engage in an End of Life Care discussion with patients. In order to empower and up skill staff, on-going training in communication skills and the development of clinical supervision strategies have supported staff in enabling reflective practice.

Key learning:

- The majority of patients who died during the period of the project had more than three Gold Standards Framework indicators present on their last admission. However, most staff felt the “surprise” question[13] was perhaps a better predictor of death within a 6 to 12 month period. ACP materials used in this project received mixed responses from both staff and patients. (For example, The British Lung Foundation booklet contained too much information for some patients and was difficult for staff to use.)
- Breathing Space have decided to create their own patient folder which can be personalised with bite size information on different elements of care which can be provided to the patient over a staggered period of time.
- Many clinical staff felt very uncomfortable with EoL care discussions.

Even when patients had three prognostic indicators present on admission, many staff indicated that an ACP discussion had not taken place.

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[12] *This included giving information to the patient, notably the British Lung Foundation ‘Guide to Coping with the Final Stages of Lung Disease’. Coping with the final stages of chronic lung disease - physical care published on “Locally Healthy” (http://www.locallyhealthy.co.uk) An adapted version of The Whittington Hospital NHS Trust patient leaflet on ‘Do Not Attempt Resuscitation’. Patients and their carers were also given information about their ‘Preferred Priorities for Care’ (PPC)*

[13] *This asks a clinician to consider whether they would be surprised if a particular patient was still alive in 12 months’ time*

Reasons for this included:

- Previous negative experiences
- A lack of confidence in their skills and abilities to address this subject
- A perception that it was not necessary
- A fear of worsening the patients' mental state by introducing the topic of dying.

Many clinical staff felt very uncomfortable with EoL discussions even when patients had three prognostic indicators present on admission. Many COPD patients also felt uncomfortable with the idea of EoL planning and were distressed when the offer of ACP was made available. These reasons are now being addressed through supervision and training.

As discussed above, an acute admission does not, therefore, appear to be the most appropriate time to instigate these discussions. The team is now considering introducing general EoL information at weekly outpatient pulmonary rehabilitation sessions. Breathing Space have decided to create their own patient folder which can be personalised with bite size information on different elements of care which can be provided to the patient over a staggered period of time.

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2. COPD CARER EXPERIENCE

2.1 A CHAOS NARRATIVE

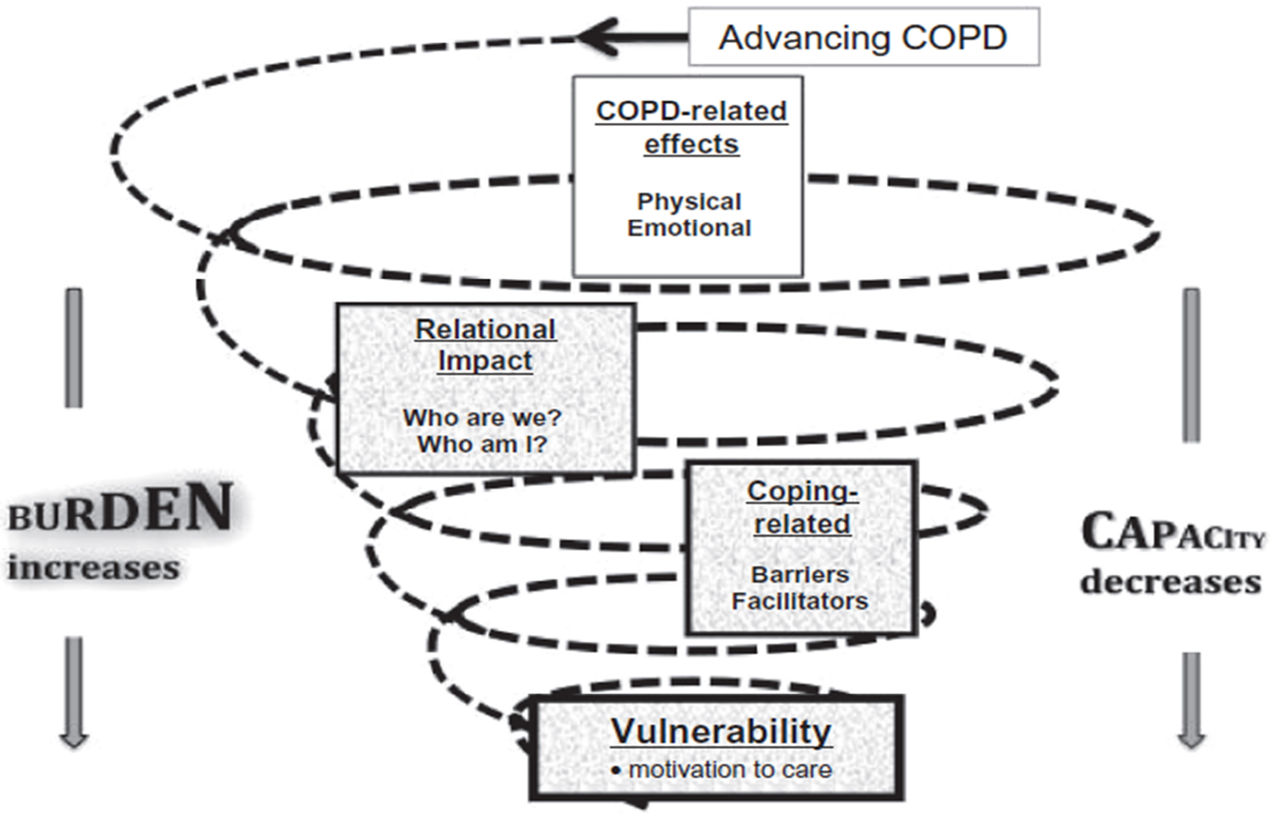
It has been estimated in the US that individuals with chronic lung disease receive an additional 5.1 hours per week of informal care when compared to those without lung disease (Figueiredo, et al, 2014). More than 70% of the COPD patients referred for pulmonary rehabilitation have one or more informal caregivers (Nakken, et al, 2015). The economic costs of COPD in terms of lost productivity from patients and carers in Europe represents an annual cost of informal care of over $2 billion dollars (Figueiredo, et al, 2014). This care, between any exacerbations requiring hospitalisation, and the physical, emotional, spiritual, relational and financial costs to carers, can alter their everyday lives forever (Simpson, 2012). Families provide a vital source of care to their relatives with COPD and the effects on them and their needs should be explored and addressed early to prevent them becoming overburdened (Figueiredo, et al, 2014).

Informal caregivers are of major importance for patients with COPD, the majority of home care for them being provided by family and friends. Caregivers provide practical help with household chores, gardening, shopping and personal care (Nakken, 2015; Janssen, 2015b; Gautun, et al, 2013). They accompany patients to medical appointments, provide emotional support, and help with the management of, and adherence to, medication use (Nakken, et al, 2015; Trivedi, et al, 2012). COPD patients with spousal carers in particular adhere to medication regimens more and smoke less compared to COPD patients without carers (Trivedi, et al, 2012).

All of this care can help reduce expensive hospitalisations and professional care costs in the home (Nakken, et al, 2015). Given that nearly half of carers are also working, accompanying patients to medical appointments, for example, can be a difficult task to fulfil (Gautun, et al, 2013). However this can be useful if they want to learn about COPD and techniques to support patients (Trivedi, et al, 2012).

Findings of US, UK, and European studies examining the nature of informal caregiving in COPD have suggested a significant burden for carers. Patients and carers may have differing expectations of the caring situation (Simpson, et al, 2010). Patients depending on carers for activities of daily living including dealing with incontinence can shift a burden of care to unexpected levels (Nakken, et al, 2015). COPD patients can be frustrated, irritable, belligerent and manifest other mood disturbances, which can impact upon family relationships and friendships (Simpson, et al, 2010; Philip, et al, 2014). Carers can become exhausted and eventual burnout can occur. This is depicted as a downward, spiralling trajectory. That is, as COPD advances, carer burden increases and carer coping capacity decreases (Simpson, Young, Donahue & Rocker, 2010).

Figure 1. The COPD carer experience



Source: (Simpson, Young, Donahue & Rocker, 2010)

A Scottish study with COPD patients and their professional and informal carers found that the severe symptoms of COPD causing major disruptions to normal life were often accepted as simply being a way of life rather than an illness. As discussed above, it was difficult to recognise and, therefore, manage end stage COPD because it was so difficult to ascertain when this was happening. Overall, COPD was a “chaos narrative” with no clear beginning and anticipated end (Pinnock, et al, 2011, 342).

This chaotic narrative is further described in terms of being a “dynamic of change, recognition, and adaptation as patients' conditions deteriorated” (Philip, et al, 2014, p421). Carers, recognising these changes, are constantly considering new approaches to their role as they continue to care throughout the trajectory of COPD and cope day to day. In addition to disease related demands, carers feel a loss of their intimate relationships, their own self-identity and they run the risk of becoming vulnerable to ill health as they attempt to balance the caring burden[14] and their capacity to cope (Simpson, et al, 2010).

Informal caregivers are a key component of EoL/palliative care for many health conditions; they are recipients of care and have significant care needs themselves. A survey set out to identify key research questions, priorities, and next steps for research on caregivers and palliative care with a view to improve caregiver health and performance. Research priorities were:

- factors influencing caregivers and roles,
- information and support needs,
- caregiver health, end-of-life issues,
- healthcare disparities,
- and delivery and costs of care (McGuire, et al, 2012).

As patients approach the EoL, schedule, financial, family and health burden increases and their health and emotional wellbeing can be severely impaired (Zakrisson, et al, 2013). Family caregivers of patients with COPD can experience clinically relevant symptoms of anxiety and depression (Janssen, et al, 2015b; Al-Gamal & Yorke, 2014). Family carers should be offered primary health care support for the sake of their own health, and to help them manage their role (Zakrisson, et al, 2013) and possibly their personal employment commitments on top of this (Nakken, et al, 2015).

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[14] *Caregiver burden refers to the physical, financial, and psychosocial hardships of caring for a loved one, usually a family member, struggling with a medical condition (Garlo, et al, 2010). Garlo, K., O’Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in Caregivers of Older Adults with Advanced Illness. J Am Geriatr Soc. 58, 2315–2322*.

Worldwide, family carers tackle the implications of caring for someone at the end of their life. This role can be relationally and personally demanding, lonely and depressing and often lacks professional, financial, and/or psychosocial support (Simpson, et al, 2010). Many COPD carers are not aware of, or receive, formal services to assist them (Grant, et al, 2012). Carers also have to accept the uncertainty of the COPD trajectory and that this could be a significant part of their lives for the foreseeable future (Janssen, et al, 2015). Caregivers' psychological response, and ability to adapt to their role, may determine their perceived level of burden. Help with adapting to the COPD caring role, therefore, could be useful (Garlo, et al, 2010; Cruz, et al, 2015). Carers' perception of the patient's health is an important factor to consider in terms of their own *subjective* burden (Nakken, et al, 2015). Their support and care needs may include physical, psychological, emotional, bereavement and spiritual support and they should be able to receive this from primary and secondary care where necessary (Currow, et al, 2011). Major themes for health care providers to recognise are: the impact of caring, the carer's role in the process and their needs from palliative care services (Gold, 2013).

A very recent narrative review has looked at the specific disease related challenges carer face. Four out of the fifteen studies analysed found positive aspects to caring reported by carers. These included carers expressing a strong sense of duty to care and satisfaction in being able to do something useful for their relative and in helping alleviate their suffering. Some found meaning in their experience, and considered it as an opportunity for personal growth. Providing care was found to be rewarding, with carers demonstrating a degree of resilience. Carers were particularly gratified when their caring facilitated patients' wishes to remain at home. Five themes emerged however in relation to carer burden: physical health, emotional, social, relational, and financial and employment impacts (Cruz, et al, 2015). These are expanded upon below in CARER BURDEN – main themes.

2.2 CARER BURDEN – main themes

Table 2 Themes emerging in relation to carer burden

Physical health

Providing care is demanding and impacts significantly on physical health, leading to fatigue and physical exhaustion due to:

- Their relative's need for constant care or supervision
- Journeying to and from hospital visits
- The co-existence of chronic conditions that increased patient's dependence on carers

Emotional health

- Caring for a relative with COPD was perceived as a stressful experience because of the unpredictability of the disease
- Carers felt anxious about leaving their relative at home
- The threat of severe and unexpected breathlessness attacks dominated day to day lives fueling constant anxiety

Sleep problems were reported due to:

- Patients' need for supervision
- The sound of the oxygen machine when sharing the same bedroom
- Patients negative attitudes and behaviours caused emotional distress to carers. For example, resistance in participating in daily activities or treatment regimens were profoundly distressing and contributed to a loss of caring motivation and alterations in feelings of intimacy towards their relative
- Carers experiencing frustration and anxiety from not receiving full explanations about the disease trajectory and management strategies from HCPs
- Carers often feeling unprepared to assume the care-giving role
- Carers reporting a lack of emotional support and respite from the services to ensure that they could continue providing care over the disease trajectory

Social impacts

- Caring for a patient with COPD is a long term commitment. Carers often need to plan their everyday activities according to patients symptoms on a given day, making it difficult to arrange activities

Role Transition

- Carers often adopt additional roles previously assumed by the patient
- Many carers experience a loss of self and personal identity, of their expected lifestyles, retirement plans, and of personal freedom.

- Social isolation and loss of recreational activities has a great impact and this appears to be associated with the degree of the patient's dependency
- Some feel unable to leave the home long enough to visit other family members and also restricted their family visits at home because of patients' disruptive behaviour
- Feelings of helplessness, guilt, resentment and frustration stemmed from a lack of time for themselves and of control over their lives

Relational

- Marital tensions between carers and patients have been reported. This can stem from, for example, patients resistance to use portable oxygen therapy
- Patients breathlessness affects patient–carer communication and can contribute to isolating the patient from their spouse and the wider family
- Spouses reported that feelings of intimacy and friendship for their partner can quickly disappear. There were changes in sexual relations or total abstinence due to patients symptoms
- Previous 'couple-hood' identity was eroded (Simpson et al. 2010)

Finances and employment

- The consequences of the disease (e.g. need for expensive medication, loss of patient's income) often led to financial strain, particularly in carers with little or no employment
- One study found that about 40% of carers of patients with advanced COPD had financial difficulties and had lowered their standard of living as a result of the disease
- Despite this, some carers with low socioeconomic status strived to improve their financial situation and secure money to rent the oxygen equipment, e.g. by looking for a job
- Other carers were often absent from their job to provide care to the patient (Pinto & Nations 2012)
- Living in a low socioeconomic context was frustrating and caused feelings of anger in care

All from (Cruz, Marques & Figueiredo, 2015) unless otherwise referenced

Additional predictors of Carer Burden include:

- carer–patient relationship quality
- carer mental component
- patient physical component
- COPD severity
- care-giving hours per week
- anxiety and depression symptoms, and self-rated mental health
- depression symptoms

2.3 CARER NEEDS AND RESOURCES

The implications of the caring role in terms of needs and resources to meet these are described below:

2.3.1 Information and knowledge

As with cancer patients, the importance of clear, timely and properly targeted information for patients at appropriate points has long been recognised by service providers. These can be provided in various formats and settings. Online information can be useful but, given the age of COPD patients, other media **may** remain important such as telephone contact and follow up as part of an intervention. Well-designed paper materials remain valuable for cancer patients (King et al, 2014) and this could also be the case for COPD patients and carers.

COPD patients and their family carers constitute a "complete patient system". Therefore, education should be available to this system about the expected course of the disease, physical and psychological care, and how to deal with an emergency (Currow, et al 2011, p 502).

If appropriate, carers should be invited to formal medical appointments for knowledge exchange (Currow, et al 2011).

2.3.2 COPD terminology

Section 9 of a booklet written by patients, carers and HCPs is a glossary of terminology surrounding COPD. This could be useful to carers although it is medically oriented (Ward, et al, 2014). Other terminology is explained in this EBS on page 142.

2.3.3 Patient & carer workshops

Patient education programme invites patients and carers to a workshop to better understand COPD. Informal, interactive workshops increase a patients' confidence, teaching them the importance of self-management and improving their quality of life. The workshops are run by the British Lung Foundation (BLF) staff together with a local clinician, nurse and physiotherapist.

Workshops aim to:

- give patients a clear and detailed understanding of COPD
- teach patients methods of self-management and ways to control their symptoms
- highlight local and regional support services
- increase patients confidence
- improve patients quality of life

Workshops include:

- an introduction to COPD
- discussion about self-management of COPD, covering the physical, emotional, medical and lifestyle aspects
- discussion about exercising with COPD
- a presentation on BLF support services
- a talk from a member of our Breathe Easy network of support groups with COPD
- a presentation on local services

2.3.4 British Lung Foundation

https://www.blf.org.uk/Page/Patient-and-carer-workshop

"Don't forget to breathe" booklet - DontForgetToBreathe.org.nz for further information and videos. (See appraisal, page 42)

The workings of the lungs - Learn about the structure of your lungs, why we need to breathe and how oxygen enters our bloodstream
https://www.blf.org.uk/Page/The-way-your-lungs-work

COPD: Chronic obstructive pulmonary disease - This information is for people with COPD, their families, friends and carers.
https://www.blf.org.uk/Page/chronic-obstructive-pulmonary-disease-COPD

Looking after someone with a lung condition - This information was updated in the latter part of 2015 https://www.blf.org.uk/Page/Looking-after-someone-with-lung-disease

2.3.5 Lung Foundation (Australia) - DVD Resources

www.lungfoundation.com.au

- How do your lungs work?
- Managing your breathlessness
- Managing treatment options
- Questions to ask your HCP
- Managing fatigue and energy conservation
- Tips for looking after yourself and your disease
- Benefits of physical activity programs and on-going support

2.4.6 Practical support

The practical needs of the informal caregivers such as education about medical aids and other resources should be assessed and addressed (Currow, et al 2011).

Local Authority Support for Carers

OT assessment for moving and handling.

Free specialist equipment may be available.

Assessing needs and determining eligibility.

http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx

2.4.7 Action plans

Action plans need a multi-faceted support programme or on-going case management to back them up. A recent rapid review suggests that if these are accompanied by a multi-faceted self-management programme or on-going case management, they will benefit patients more. Self-management programs (in which action plans may be one component of the intervention) have shown benefits for individuals with COPD in terms of reducing hospital admissions, improving exercise capacity and health-related quality of life.

Action plans with or without education sessions up to 1 hour in length, compared with usual care can:

- significantly increase antibiotic and corticosteroid use during an acute exacerbation, and
- significantly increase patient knowledge about COPD and what actions to take during an exacerbation.

However, action plans do not impact health care utilisation or other clinical outcomes including health related quality of life, mortality, lung function, functional capacity, symptoms, anxiety, or depression (Health Quality Ontario 2013).

A management plan is essential to assist with the understanding of medications (Ward et al, 2014).

2.4.8 Finances

As with cancer patients, the costs of illness can impact upon patients and carers. Travel to appointments and taking time off work can be costly for carers (King et al, 2014).

Personal health budgets have been reported to have positive impacts on health, health care and relatives/family. Although issues arose around agreeing acceptable uses for their budget and delays could occur in procuring chosen services or equipment, flexibility in how future budgets are used may allow maximum benefits to be derived.

- Clear information about what budgets can and cannot be used for, with suggestions offered would be beneficial.
- Budget holders are likely to benefit from regular contact with staff for reassurance and continued motivation (Davidson, et al, 2013).

The following financial support and benefits should be explored:

- DWP
- Grants
- Taxi cards
- Blue badges.

Please also see: Appendix 1. Suggested curriculum for "General education and support for carers at the end of life", Module 2 (page 159) for more informaton on accessing financial support and benefits and resources/downloads for this.

2.4.9 British Lung Foundation

- Care and mobility.
- Information on Personal Independence Payment (PIP), Disability Living Allowance (DLA), and Attendance Allowance (AA).
- People unable to work
- Information on Statutory Sick Pay (SSP), Employment and Support Allowance (ESA), and Universal Credit.
- Conditions caused by work
- Information on Industrial Injuries Disablement Benefit (IIDB).
- Information on Carer's Allowance, Carer's Credit.
- Top-up benefits
- Information on Income Support, Tax Credits, Pension Credit, Housing Benefit, Council Tax Reduction, and Social Fund Payments.
- Help with heating costs
- Information on Winter Fuel Payments, Cold Weather Payments, and Warm Home Discount Scheme.
- Special rules for terminally ill people
- Information about benefits you might be entitled to get quickly if you are not expected to live for more than six months.

https://www.blf.org.uk/Page/Financial-support

3.0 Patient and carer needs and resources in advanced COPD

3.1 EoLC conversations

"It's not easy to talk about end of life issues but it's important to do. Now that we've put our affairs in order and talked about what we want, we can "put that in a box" as it were, and get on with living one day at a time, cherishing each day together, as I know it's going to end one day"

(Carer of patient with COPD).

"If you talk about it, you can make the most of life".

(COPD patient)[15]

EoL care focuses more on the final stages of the illness and has been defined as care that 'enables the supportive and palliative care needs of patient and family to be identified and met throughout the last phase of life and into bereavement'. However, as discussed above, prognostication in COPD is very challenging and can result in a 'prognostic paralysis' and, because prognosis is so uncertain EoL issues are not addressed[16] (Momen, et al, 2012).

Alongside every day caring issues, EoL, ACP and DNACRP conversations need to be addressed as part of the advancing trajectory of COPD. In a study involving people with advanced COPD, their carers, an expert panel, service providers and community groups found that there was a lack of care planning conversations, and communication between all parties involved was, in the main, insufficient (Crawford, et al, 2012). Ideally, EoL discussions, including resuscitation and intubation wishes, and ACP, (potentially including taking out a medical enduring power of attorney), should occur in an outpatient setting when a patient's condition is relatively stable or alongside curative-restorative care (Patel, et al, 2012).

A systematic literature review and narrative synthesis was undertaken to examine the evidence reporting on EoL conversations between patients with COPD and their healthcare professionals (HCPs) with respect to:

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[15] http://dyingmatters.org/story/told-dying-matters

[16] *More definitions are below in*
17. Clarifying terminology for carers *on page 141*

- the prevalence of conversations
- each party's preferences for timing and content
- facilitators and blockers to these conversations

Barriers, cues and facilitators to EoL care include:

- the difficultly in prognostication in COPD which leads to uncertainty over when discussions should begin
- poor understanding of COPD among the general public
- many HCPs do not identify EoL discussions as their responsibility (Momen et al, 2012).

Most patients reported that they have not had EoL conversations with HCPs. Whilst many patients would like these conversations, a potentially large minority would not, i.e. patients' preferences for EoL conversations vary greatly. HCPs should, therefore, respect the wishes of those not wanting to discuss EoL meanwhile providing multiple opportunities for those who wish these discussions to take places (Momen, et al, 2012) and for those who subsequently change their mind.

Many COPD patients and families are not being given the opportunity to have such discussions due to a wide range of barriers.

Only a minority of patients report having discussed EoL care with their HCPs. HCPs, despite recommendations, rarely begin EoL discussions. The evidence shows that a range of patients want more information about their illness and the future. Some want all available information to enable planning ahead. However, about 50% of patients do not want this because it would distress them and they would rather wait until their COPD was more advanced (Momen, et al 2012). Those patients who do not wish to talk about death, dying or EoL care in relation to their COPD should have their wishes respected (NHS, 2011). This presents a dilemma for HCPs however, in identifying the patients that do want to know their prognosis early. Even when patients initiate such conversations, although doctors find this easier but they still feel uncomfortable about it. In practice HCPs report that discussions often take place when the patient's health has deteriorated and they may be too unwell to make decisions. While some suggest discussions should be early in the illness, in practice this rarely occurs. A good rapport with the patient, experience in dealing with EoL matters, adequate training in breaking bad news and specialist knowledge are seen as particularly important (Momen, et al. 2012).

Whichever clinical setting they take place in, EoL conversations are challenging for everyone. However, this patient-clinician communication can improve outcomes for patients and families, and are especially relevant for patients with COPD. HCPs can gain an understanding of their patients' values and preferences for life-sustaining treatments as well for their choice of site of terminal care. Effective patient-clinician communication is needed to inform and prepare patients about their diagnosis, treatment, prognosis and what dying might be like. The challenge remains in the practical implementation of ACP in the COPD clinical setting.

Doctors themselves find instigating EoL conversations very difficult and feel that patients are not ready to engage in these. They are reticent to take hope away from families, and are not adequately trained in this task and/or have no formal protocols to follow. Also, avoiding these discussions may give false hope and deny patients the opportunity to prepare and plan, thus a balance needs to be struck between optimism and realism. HCPs need to give patients time to get used to their poor prognosis, 'redirecting' them from hope for recovery to facilitating a good death (Momen, et al, 2012).

Transition points can be opportunistic junctures which can prompt professionals to open up discussions about the nature of COPD and the outlook for the future. The **point of diagnosis, retirement for medical reasons, the point at which domiciliary oxygen is needed, or during hospital admissions**, are all characteristic transition points of the COPD trajectory which could trigger discussions with patients and carers about ACP, palliative approaches to care, and EoL issues. Clinicians should communicate and explain the current clinical situation and the management approaches. Other, specific clinical points at which to instigate conversations may include:

- FEV1 < 25%
- oxygen dependence
- respiratory failure
- heart failure or other comorbidities
- weight loss or cachexia
- decreased functional status
- increasing dependence on others and
- advancing age

For people with COPD nearing the end of their life, it is important that they are given a choice about where they are cared for, and where they die. Whilst most deaths occur in hospital, most people say they prefer to die at home. Changing this will require improving the support that is available in the community and there are moves afoot to support people who choose to die at home (including a care home) to do just that and receive the support that they need (Department of Health, 2011).

3.2 Advance care planning (ACP)

ACP is a process of discussion about goals of care and a means of setting on record preferences for care of patients who may lose capacity or the ability to communicate in the future and implementing them is widely promoted by policy makers. A patient, in consultation with healthcare providers, family members and other loved ones, makes decisions about their future healthcare (Nakken, et al, 2015). In England and Wales, 'advance decisions to refuse treatment' (ADRTs) have a legal force under the provisions of the Mental Capacity Act (Seymour, et al, 2010). ACPs lay out a person's wishes for EoL care and cover a range of non-medical issues. They must be considered by lay and professional carers when providing treatment but they are not legally binding – unlike Advanced Decisions, (see below, p41) (Kitzinger and Wilkinson, 2015).

The End of Life Care Strategy for England advocates that all patients with advanced, progressive, incurable illness should be given the opportunity to participate in ACP. The recent Department of Health Strategy Document for COPD (Department of Health, 2011) and its companion document (Department of Health, 2012) emphasises EoL care, structured hospital admission and specialist intervention. There is a growing recognition internationally of the need for patients with advanced COPD to receive education about prognosis, EoL care and ACP (Seamark, et al, 2012). Giving people the opportunity to discuss their wishes around issues such as resuscitation and representation on loss of capacity is important and should be undertaken when the patient is as well as possible (NHS 2011).

The use of ACP at the appropriate time has yielded positive feedback from patients and carers (NHS, 2011). It has been noted that family members of elderly patients who received facilitated ACP had fewer symptoms of post-traumatic stress, depression and anxiety compared with family members of patients who did not do this. However, ACP, in which communication about EoL care is an essential part, occurs infrequently in patients with COPD (Nakken, et al, 2015; MacPherson, et al, 2012; Seamark, et al, 2012).

From the patients' point of view, hospitalisation for COPD is not the best time to talk about ACP given the busy nature of admission and discharge, and that patients are often extremely ill. None of the patients in one particular study recalled any talk about resuscitation or planning for the future. However, there was evidence that given empathetic and knowledgeable support, these discussions could be initiated, with some patients preferring to talk to their general practitioner (GP) and some wanting to avoid these discussions altogether. A possible middle ground is that, as with EoL conversations, while periods of hospitalisation may not be an appropriate time to initiate discussions around resuscitation, ventilation, and ACP, these admissions could be taken as a milestone in the trajectory of COPD which could lead to such discussions by GPs when they subsequently visit patients and carers at home following discharge (Seamark et al, 2012).

Adding to what little is known about how people with severe COPD, MacPherson et al (2012) found that patients feel that they do not receive enough information about their diagnosis and prognosis, and want deeper discussions with HCPs with more involvement in decisions about their treatment when those decisions were required. Patients are happy to discuss their general views about future care, but feel uncomfortable with the traditional model of binding 'advance directives'. Considering ACP as an on-going process of discussion of prognosis, concerns and probable preferences for care could be more useful than encouraging binding advance decisions. A local coordination of who is responsible for information provision is necessary, and greater involvement of patients with COPD in management decisions as they arise would fit in with a process approach (MacPherson, et al, 2012).

Community palliative care nurses are centrally involved with patients with palliative care needs who may wish to set on record their views about future care and treatment. They perceive ACPs as an important part of good nursing care and practice. ACPs facilitate not only engagement with patients about care preferences and family communication, but can also enable a shift of care focus towards palliative care. They found ACPs challenging however, in terms of timing, team working and managing the focus on 'check list' instructional directives which relate poorly to patients' concerns and – facilitating family discussions about differences in views. That is, barriers to completing ACPs include a lack of resources, lack of public awareness about ACP and difficulties in talking about death. Education on this subject for HCPs should include, design of realistic scenarios and a flow chart (Barnes, et al, 2012; Seymour, 2010).

Training resources for HCPs for this area of practice are described below, namely, "SAGE and THYME" and "e-LFH HEALTH EDUCATION ENGLAND" and Advanced Decisions Assistance (charitable organisations) (see page 99).

3.3 Advanced Decisions

There is a difference between ACP and Advanced Decisions, the main one being that Advanced Decisions (ADs) are legally binding. If anyone goes against a patient's choices this could be considered a criminal offence. ADs must do the following:

- Genuinely reflect a person's wishes - *they must understand terminology relating to palliative and EoL care so they can consider various options open to them*
- Be available when needed - *there is no national repository for these at present. One copy needs to be with a GP, put on their medical record and available to other HCPs and trusted family and/or friends*
- Meet with compliance by Health care providers or the Courts if necessary - *refusals to accept treatment will be respected, especially if endorsed by family and friends of the patient* (Kitzinger and Wilkinson, 2015).

3.3.1 ADA (Advances Decisions Assistance)

ADA is a psychology based support charity is a charity set up in June 2015 to; raise awareness of ADs and help people to write them (including simple examples and one to one support); provide training for GPs, and other HCPs; conduct and support research into ADs. It takes into account psychological theory and empirical evidence relating to ADs, incorporating knowledge of psychological barriers for thinking and planning for death, communication issues in EoL conversations; the variable stability of treatment preferences; 'false memories' for decisions and failures in predictive capacity for EoL preferences. The founders of this charity have expertise in ADs through an ESRC funded seminar series on ADs and through collaborative research with another charity; Compassion for dying. They provide training to professional carers, neurologists, GPs and for psychologists - who are ideally placed to support individuals in writing ADs. However, they would need training in the legal, ethical and medical issues associated with ADs.

http://adassistance.org.uk/
info@ASassistance.org.uk
01757 289453

Further information about ADs is also available form a number of other charity based websites:

- Compassion in dying (http://compassionindying.org.uk/)
- AGE UK (www.ageuk.org.uk/)
- Alzheimer's society (www.alzheimers.org.uk/)
- Motor neurone disease association (www.mndassociation.org/)

3.4 Do Not Attempt Cardio Pulmonary Rehabilitation (DNACPR)

ACP is important in COPD in terms of a person wanting or not wanting artificial ventilation under any circumstances. What makes it more difficult to begin this particular discussion is that many patients simply see COPD and its symptoms as part of a normal aging process. Unlike other conditions, COPD creeps up on people and is part of their life and they passively accept it as such. This will make it difficult for them to shift from a mind-set of passive acceptance of their medical problem to accepting that they have a life limiting illness which needs attention to various aspects of its course.

3.5 Written resources

3.5.1 Difficult conversations for COPD

This booklet is based on discussions with around sixty people affected by COPD (patients, carers and former carers) how, when and with whom they would like to have conversations about EoL care. The guidance is based entirely on these discussions and represents their unique perspective, containing practical hints on what and what not to say.

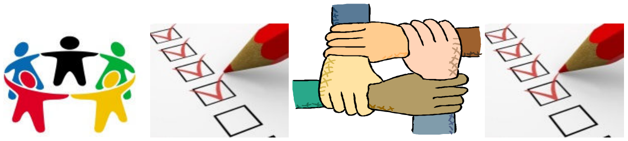
This guidance was produced with support from the British Lung Foundation and the Department of Health.

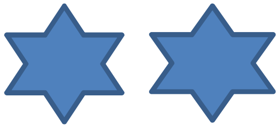
http://shop.ncpc.org.uk/public/shop/default.aspx?Category=Difficult%20conversation%20series

3.5.2 Don't forget to breathe

http://dontforgettobreathe.org.nz/

A guide for patients with COPD and their carers. This publication from New Zealand has a useful section on Palliative and End of Life Care for patients and carers. The whole book is appraised here.





This is a substantial read of over 90 pages initiated by a COPD patient and supported by the authors above. Thus is not a book written by HCPs for patients but one written as a partnership between patient, carer and the healthcare team. Ten book sections break it up into manageable chunks of very in depth information, some of it very practical and sensible. Section headings are below, however, an appraisal follows of: Section 5, Living with COPD, I, EOL care options; Section 6, Living With COPD Dealing with Exacerbations; Section 7, Complementary Therapies; Section 8, Caring for the Carers; and Section 9, specifically relating to Palliative and EoL care. Comments and recommendations specific to NZ are omitted unless they could pertain to the West of England.

Section 5. Living with COPD. Pulmonary Rehabilitation

I) EoL care options

This section very briefly addresses ACP and the recent movement in the West, to bring dying into the conversations of people and carers of those with advanced disease, instead of these being the sole arena of HCPs. ACP is slowly being introduced throughout NZ, with key HCPs being trained to help people with these, including artificial ventilation, artificial hydration and feeding.

Section 6. Living With COPD. Dealing with Exacerbations

Exacerbations are very difficult to live with for patients and carers and prompt treatment of the symptoms is vital. Ways to do this are explained and the need for regular reviews by HCPs of lung function, oxygen levels, management plans and the checking of weight, diet and exercise tolerance. This is expanded upon in lay terms and what the management plan should contain when feeling well, and when it ‘steps up’ to cover worsening of specific symptoms (sputum for example) and that by beginning a management plan sooner rather than later can decrease hospital admissions.

It highlights NZ schemes which can loan urinals, commodes and oxygen short term. A hospital stay should include information and education regarding management of COPD and preventing another hospital admission and the need to keep mobile. Patients should leave hospital with a management plan for next time an exacerbation occurs or an updated previous one.

There are many details of living with COPD, for example, including advice on air travel and that portable oxygen concentrators and nebulisers, which are flight compliant are available and for passengers with lung disease there is the concern that altitude exposure may exacerbate low blood oxygen. Pre-assessment flight check is crucial for anybody who has severe COPD, those within 6 weeks of hospital discharge for acute respiratory illness, those who have recent pneumothorax, and those who have pre-existing requirement for oxygen or ventilator support (Edvardsen, et al, 2012).

Section 7. Complementary Therapies

Acupuncture, aromatherapy, herbalism, reflexology are all covered in depth nicely in this section, and for those that are interested in complementary therapists gives details of dosages and how they can help with COPD's physical, emotional, psychosocial and spiritual symptoms.

Section 8. Caring for the Carers

This short section acknowledges the strain on carers (labelled as "unsung heroes") offering simple advice to keep them mentally and physically well including; **Getting Out and Keeping Healthy**; **Getting as much information about COPD as possible**; **taking Help When it is offered or Ask for Help and; Coping With Stress,** including, **feelings of helplessness or frustration** – not being able to help someone get better, or prevent their death; **fear** – about the future, or not knowing what to do; anger – that this is happening, that people don't understand the demands, that people don't help; **grieving** – for the future you would have had if COPD hadn't come along; **guilt** – about feeling helpless, angry, fearful or grief and that these are normal for COPD carers. It offers NZ telephone help lines, suggests talking to GPs or obtaining free counselling and identifying aids which can help them or their patients cope day to day on managing tasks.

Section 9. Palliative and EoL Care

This section clarifies misconceptions about what Palliative Care is, defining it as "care for people of all ages with a life limiting condition" and, in the case of NZ where palliative care is offered, i.e. in hospices. And that aging and the progression and worsening of respiratory disease may precipitate a referral to palliative care services. It talks about key principles of palliative care, its approach to affirming life that dying is normal and that families of COPD patients also have needs. Specific to COPD palliative treatment of breathlessness is discussed at length especially the role of morphine elixir and midazolam.

Who and when people should be referred for palliative care is discussed, with specific factors to consider and highlighting the value of palliative care in conjunction with active medical treatment. ACP is addressed again in this section, and factors about their life, values and possessions for patients to consider are suggested. Also, gaining advice about medical treatments and their benefits and risks is useful.

Overall this is a very useful booklet for COPD patients and carers. The booklet concentrates on COPD as a disease and as it stands, this information is useful to carers. It offers vignettes and examples of patient experiences of COPD. Section 9, the Glossary explains the terminology HCPs use and naturally this is medically oriented. The language generally is mixed and some sections require more or less concentration to read and understand this. However, different sections can be assessed according to need. Within section headings are clear and can help locate information a patient or carer may need at particular points in their disease trajectory. End of Life is not covered in depth in terms of processes and physical changes.

http://dontforgettobreathe.org.nz/

3.5.3 Coping with the final stages of chronic lung disease

This five page booklet http://shop.blf.org.uk/products/coping-with-the-final-stages-of-a-lung-condition has clear, concise sections on:

1. How can you tell when someone with chronic lung disease is entering the last phase of their life?

2. Controlling symptoms

- Anxiety
- Depression
- Fluid retention
- Loss of appetite
- Coughing
- Chest pain
- Fatigue and sleep disturbance
- A flare-up

3. Taking control – your choices (this includes introducing ACPs) asking the questions

- Do you want to be admitted to hospital if you have a bad flare-up?
- Would you want to have non-invasive ventilation?
- Would you want to go into an intensive care department and go on life-support?
- Would you agree to resuscitation if your heart or lungs stopped working?
- Where would you like to be cared for towards the end of your life?

4. The last few days of life

5. Caring for a loved one at the end of life

6. Health team support

7. Palliative care

One study exploring prognostic indicators initially using this resource found that it contained too much information for some patients and was difficult for staff to use and this project has since constructed their own booklet for patients.[17]

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[17] *NHS Improvement - Lung National Improvement Projects (2011) - Improving end of life care in chronic obstructive pulmonary disease (COPD): testing the case for change. "Breathing Space": Prognostic indicators and advance care planning in chronic obstructive pulmonary disease (COPD) Rotherham. See page 28 above*

4. COPD disease specific issues and support available

Although it could be argued that carer burden may not be disease specific (Garlo, et al, 2010), at EoL with COPD this is not the case. It brings with it particular and specific symptoms, the main ones being shortness of breath and reduced exercise ability, together with a cough and production of phlegm that may exacerbate over time. The next most common symptoms are tiredness and decline in overall well-being – all impacting upon caregivers. There is a large section on breathlessness below because it is a prevalent and severe symptom which causes both patients and carers acute anxiety (Horton & Rocker G, 2010).

Following this, Table 2 Themes emerging in relation to carer burden, p30 then draws together other identified main issues for carers and the knowledge, resources and training they need and/or can access to manage these.

4.1 Breathlessness

Breathlessness is particularly high in COPD affected around 56-98% of patients (Ekström, et al, 2015). Although it can be devastating for patients, they do under report it, and clinicians are uncertain how to manage chronic intractable breathlessness and may not actively assess this complex symptom. It is the result of an interaction among multiple physiological, psychological, social and environmental factors, which act as moderators in the quality and the intensity of a person's perception of breathlessness and can result in secondary physiological and behavioural responses.

Breathlessness develops gradually and patients adapt commensurately to the restrictions it imposes, only presenting with this to HCPs in a crisis when an early, full disclosure of the nature and course of breathlessness is crucial in order to manage it. It causes disability, distress, anxiety, panic and fear of dying – many patients seeing this as their worst symptom. The consequences of breathless are troubles with breathing, impaired mobility, anxiety (Farquhar, 2010) restricting them to the home, isolating themselves and their carers (Booth, 2013) and a growing dependence on carers (Farquhar, 2010).

Breathlessness threatens carers because it is difficult to cope with and they feel helpless when presented with this symptom. Patients can become angry if family carers suggest they adopt coping strategies for this symptom. Breathlessness complicates management of COPD especially in the final year of life and this can trigger anxiety or depression in patients and caregivers as its severity increases (Janssen, et al, 2015).

Breathlessness is manageable however, by specialised palliative care. A multidisciplinary team approach including carers can address the psychosocial dimensions of the symptom and the pathophysiology of the sensation. Science and translational research has made great advances over the last 20 years. If this approach was implemented by all doctors, the quality of life of COPD patients and their carers could be improved. As palliative care has made an acknowledged, global impact on pain control, breathlessness (which has similar subjective qualities) can similarly be addressed. Breathlessness services, such as those described below, have led to improved access to palliative care for all patients with respiratory disease. These services work with the patient, family and referring team until no further improvement is possible. They accept re-referral or ensure continuing links with palliative care. Unlike cancer patients with breathlessness, COPD patients can live much longer. The multidimensionality of breathlessness affecting patients and carers can be addressed by complex interventions combining non-pharmacological and pharmacological interventions to improve quality of life and significant clinical improvement (Janssen, et al, 2015).

Like pain control, patient centred interventions tailored to individual and family needs can have a large impact. HCPs however, need to know that these are evidence based and effective. A classification for non-pharmacological interventions is now under development. Non-pharmacological interventions (such as the BIS) are those that can be grouped as those that affect:

1) Breathing, most likely to work by affecting the neurophysiological pathways, central and peripheral, involved in generating dyspnea, for example, fan, opioids, breathing exercises and neuromuscular electrical stimulation (NMES)
2) Thinking, an intervention that targets central perception of breathlessness, such as active listening, cognitive behavioural therapy (CBT), education and relaxation techniques; and
3) Functioning, targeting mobility, for example, pacing skills, mobility aids and a personal exercise program.

Often interventions will involve one or more of these factors and the manner in which the intervention is delivered will affect the outcome and encourages engagement in patients and carers (Booth, 2015).

Following a brief introduction to CBT for breathlessness, interventions for breathlessness are described below. These include two completed initiatives (BSS) and (BIS) and one currently on-going (living with breathlessness).

4.1.1The Breathlessness Support Service (BSS)

✡ ✡

This NIHR RCT compared the Breathlessness Support Service (BSS) to standard care demonstrating that patients who received the BSS had, at 6 weeks, significantly improved mastery of their breathlessness. It is the first study to test earlier, integrated palliative care in non-cancer as well as cancer patients. Through close collaborative working, and with the patient centre stage, experts in palliative care, respiratory medicine, physiotherapy and occupational therapy were able to support chronically breathless patients to much better control this frightening sensation.

BSS is a short-term service mainly delivered from outpatients as a single point of access. This low-cost BSS focused on patients with refractory breathlessness, where breathlessness persists at rest or on minimal exertion. Those affected have high healthcare needs, poor quality of life, many symptoms in addition to breathlessness and are frequently admitted to hospital.

The BSS consists of two outpatient appointments and a home visit, this included an information pack and individually tailored treatments to help manage breathlessness.

4.1.1a BSS specific components

A combination of management strategies (education of patients and use of specific therapies) including:

- breathing exercises
- relaxation techniques
- education
- the fan
- discussions around crisis management
- information or interventions to help improve muscle strength to increase mobility and function
- lifestyle modifications/pacing
- talking and active listening by the BSS team.
- a person-centred approach applied by caring and skilled staff

Patients reported that the BSS, through its holistic approach to the management of breathlessness provided them with skills and interventions to better manage their breathlessness and also additional coexisting symptoms including pain and immobility.

- BSS improved quality of life and the way patients managed their breathlessness
- BSS patients scored 16% higher in a measure of breathlessness mastery[18]
- BSS patients survival rate was 94% compared to 75% in those who did not receive this
- Most symptoms and psychological problems improved in the BSS group, and mostly deteriorated or did not change in the control group
- Costs of care for the two groups were similar, so this service does not seem to be more expensive than usual care.

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[18] *This assessed patients' feeling of control over breathlessness, and its effects on quality of life and function led to better quality of life and survival rates for patients with lung disease and cancer.*

Key themes were identified as being especially valuable:

- personalised care
- empathic staff
- the joint physiotherapy and occupational therapy at home
- importance of patient education to empower patients and
- effectiveness of context-specific breathlessness interventions

Components useful in any future breathlessness service would include:

- a combination of personalised care
- empathic staff
- education and empowerment
- use of specific interventions
- information about other services (e.g. community palliative care and pulmonary rehabilitation).

4.1.1b Appraisal

For a small, short term, inexpensive small study this one illustrates that a complex intervention individualised to a patient's individual circumstances is very helpful in the context of refractory breathlessness. Patients felt empowered through the BSS and specifically, the educational component. Particularly important was that patients survived longer and the BSS acknowledged the complexity of breathlessness in the presence of coexisting symptoms was personalised to each patient (Reilly, 2015).

4.1.2The Breathlessness Intervention Service (BIS)

A single-centre Phase III fast-track single-blind mixed-method randomised controlled trial (RCT) of BIS versus standard care with 67 participants was conducted; the control arm receiving BIS after a two-week wait.

The BIS is a multi-disciplinary complex, theoretically driven intervention underpinned by a palliative care approach, utilising evidence-based non-pharmacological and pharmacological interventions to support patients with advanced disease. It sought to establish whether BIS was more effective, and cost-effective, for patients with advanced cancer and their carers than standard care.

The primary outcome measure was a rating scale for patient distress due to breathlessness at two-weeks.

- Secondary outcomes were evaluated using:

- The Chronic Respiratory Questionnaire
- Hospital Anxiety and Depression Scale
- Client Services Receipt Inventory
- EQ-5D
- Topic-guided interviews

The BIS reduced patient distress due to breathlessness significantly more than the control group. For the majority of participants the BIS:

- reduced fear and worry
- increased confidence in managing breathlessness
- Patients and carers consistently identified specific and repeatable aspects of the BIS model and interventions that helped
- How interventions were delivered was important
- BIS legitimised breathlessness and increased knowledge whilst making patients and carers feel ‘not alone’
- BIS had a 66% likelihood of better outcomes in terms of reduced distress due to breathlessness at lower health/social care costs than standard care
- BIS appears to be more effective and cost-effective in advanced cancer than standard cae(Farquhar, 2014).

The problem solving approach has been very valuable for patients and carers participating in the BIS over the last 10 years(Booth, 2013).

http://www.cuh.org.uk/breathlessness-intervention-service-bis/about/what-we-do

4.1.2a Contents of BIS

Initial consultation

- Patient assessment re the impact breathless has on life and carers’ lives
- Things already being done to alleviate it
- Discussion about additional tools that can help i.e.
    - Fan
    - Breathing techniques overall effort of breathing
    - Breathing retraining
    - Secretion clearance
    - Mindfulness and Relaxation
    - Acupuncture and acupressure
    - Exercise
    - Anxiety management.

  - Energy conservation and activity pacing
  - Pharmacological Management
  - Psychological assessment and support

http://www.cuh.org.uk/breathlessness-intervention-service-bis/about/what-we-do

4.1.2b Intervention resources

The Cambridge BIS Manual. This is aimed at clinicians and is based on evidence. It describes practical techniques for helping the breathless patient which have been tried and tested in the BIS and by other centres researching the symptom and working with breathless patients across the world.

To purchase a copy, please contact bis@addenbrookes.nhs.uk

The Cambridge BIS toolkit The BIS toolkit was originally developed as a teaching tool. The BIS toolkit consists of a set of memo cards containing useful advice for both patients and clinicians.

Having received very good feedback from clinicians who had been given the tool, it has been decided to improve it and make it available more widely.

Available soon. Price to be confirmed. If you would like to register your interest while this kit is being improved please contact: bis@addenbrookes.nhs.uk

4.1.2c Managing breathlessness in clinical practice

This book is an invaluable resource for those working in the respiratory medicine, oncology, cardiology and other specialties where breathlessness is commonly managed although less recognised like nephrology and neurology. It will be of help to occupational therapists, physiotherapists and specialist nurses as well as physicians. It will also be of interest to anyone who wishes to increase their knowledge of the advances in evidence that now enable clinicians to offer much improved care for those suffering with frightening symptom of breathlessness.

To purchase a copy please contact: bis@addenbrookes.nhs.uk

4.1.2d BIS Resources

BIS Fact sheets – includes information on a) breathlessness, b) breathing methods and positions to ease breathlessness, c) handheld fan, d) managing your energy, e) relaxation, f) shortness of breath and your diet, g) mindfulness, h) self-hypnosis.
http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/patient-information-leaflets

BIS audio resources
Relaxation CD
Relaxation and Introduction to Mindfulness. Tracks include:

Relaxation body scan	09:15
Body relaxation	08:03
Letting go of anxious thoughts	07:34
Visualisation technique	07:16

http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/practical-tools

BIS Relaxation scripts

- Body Scan
- Letting go
- Visualisation

http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/video-and-audio-help-manage-breathlessness

BIS DVD Resources
http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/video-and-audio-help-manage-breathlessness

Causes of breathlessness
This film introduces and explains the physiology of breathlessness and the effects using male and female actors. It offers knowledge about the symptom and that, in itself, it is not dangerous. It tells of strategies such as using a fan, mindfulness, CBT and other psychological techniques. It offers knowledge and normalises this symptom, so that people can gain control over their breathlessness and think about ways in which they can live with it.

Using a handheld fan to reduce breathlessness
About subjective feelings of breathless and messages from brain heart and body with demonstrations and diagrams to illustrate how using a hand held fan can work. This can work as well as, or better than, oxygen therapy

4.1.3 IMPRESS patient breathlessness booklet

IMPRESS “BITs” for patients are based on the IMPRESS programme and constitute guidance for patients, clinicians, commissioners, and researchers about how to improve the care for people bothered by breathlessness.

4.1.3a Appraisal

This 11 page booklet offers guidance to patients with COPD and heart failure. It offers general advice about:

- why patients experience breathlessness
- managing anxiety and offers
- breathing techniques and control.
- general good life style advice related to alleviating breathlessness.
- evidence-based coping tips
- Nutritional guidelines including:
    - Nutritional Guideline for COPD
    - Eating Well for Your Lungs
    - Improving Your Nutrition
    - Nutrition Support in COPD
- Links to other support

4.1.4 Living with Breathlessness study – on-going study

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The Living with Breathlessness study is a collaboration between Cambridge, King’s College London and RAND Europe seeking to identify trajectories of patient and carer need and preferences for care in advanced COPD (funded by Marie Curie Cancer Care and an NIHR Career Development Fellowship)

The Living with Breathlessness study is a programme of work that seeks to provide new evidence on the trajectory of care needs and preferences of patients with COPD and their informal carers.

Using a novel flexible approach to data collection which combines longitudinal methods, mixed methods, and multiple perspectives, the study aims to capture care needs as experienced by patients and informal carers over time, and the clinician-identified barriers and facilitators to meeting needs. This new evidence will better our understanding of how patients' and their informal carers' needs and preferences change over time and how they can be better met.

Running across the East of England and South London until 2015, the study has an overall recruitment target of 500 patients with COPD.

Funded by Marie Curie and the National Institute for Health Research (NIHR), and supported by the Primary Care Research Network (PCRN) and service users, the study's multidisciplinary team include respiratory and palliative care clinicians, as well as primary care health professionals, NHS managers and academic researchers.

http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/

4.2 Cognitive behaviour therapy for breathlessness

There is evidence for the effectiveness of Cognitive Behaviour Therapy (CBT) in addressing mental health difficulties in COPD. It is also important to integrate a mental health model with a framework of adjusting to a physical health condition. Identifying people's idiosyncratic beliefs about their COPD, its emotional impact and their coping strategies, can help formulate and address their difficulties within this physical health context. The cognitive-behavioural model explains panic for example, as a vicious cycle of catastrophic appraisals of breathlessness, escalating fear and heightened physiological arousal. This pattern may be reinforced through observing the reactions of observers, who may feel equally frightened and helpless. The culmination can often be an overreliance on medications, over-monitoring of symptoms and inappropriate presentation at emergency services. Individuals may start to mistakenly avoid activities due to fearful beliefs about the consequences of becoming breathless, leading to isolation, depression, continued smoking and a lack of motivation and energy for self-management.

Using CBT principles are: The COPD breathlessness manual (see below), the four week group cognitive-behavioural breathlessness intervention and the COPD CBT Care study for depression

There are also current initiatives which are testing the training of respiratory and community COPD nurses in CBT skills (Heslop, et al, 2013; Barker et al, 2014).

4.2.1 The COPD breathlessness manual (RCT)

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The COPD breathlessness manual (CM): An RCT to test a cognitive-behavioural manual versus information booklets on health service use, mood and health status, in patients with chronic obstructive pulmonary disease

The CM is the first known ‘manualised’ psychological intervention, targeting breathlessness, panic and prevention of hospital use in COPD. This programme demonstrated clinical and cost-effectiveness, was acceptable to participants, and has the potential to be used in both primary and secondary care. Results indicated that the CM provided psychological benefit, improved self-management and reduced costs to the NHS in an unselected group. It is emphasised that it should be considered as an option for the majority of COPD patients as a preventative measure, to help them cope better.

222 COPD patients were randomly allocated to receive either the COPD breathlessness manual (CM) or Information Booklets (IB).

They were instructed to work through their programme at home, over 5 weeks. Guidance from a facilitator was provided at an initial home visit plus two telephone call follow-ups.

The COPD breathlessness manual (CM) was developed as a guided self-help intervention that individuals complete in their own time at home, with support from a facilitator. It applies CBT techniques within a self-management framework and specifically targets the cognitive-behavioural aspects of breathlessness and panic which may facilitate greater improvements in health outcomes than PR alone. The CM was developed by a health psychologist, with multidisciplinary team input and piloted with small focus groups of COPD patients over 6 months.

Final version consists of a 5-week intervention, with each week divided into six sections, for example, Week 1: ‘Understanding COPD and the experience of breathlessness’ was divided into the following six sections:

- Section 1: What is COPD all about?
- Section 2: Focus on breathlessness -Part 1
- Section 3: How to control breathlessness and panic
- Section 4: Daily exercises
- Section 5: Relaxation CD: Introduction and exercise 1: Breathing control
- Section 6: Summary and weekly record

The main theme was breaking the cognitive-behavioural maintenance cycle of breathlessness, panic, frustration and depression, with a specific focus on strategies to manage distress (for both patients and carers) to ultimately prevent inappropriate A&E attendance and hospital admissions.

- Education on distinguishing between a COPD exacerbation and a panic attack was provided alongside self-management guidance
- Shifting unhelpful illness cognitions and encouraging adaptive behaviours using pacing and goal-setting was a central strategy
- Breathing control and mobility exercises were demonstrated and trialled and participants were encouraged to practise these daily
- Participants were asked to complete self-help tasks as well as a weekly mood and breathlessness rating

The manual was accompanied by a relaxation CD.

The control group received British Lung Foundation COPD booklets and were encouraged to work through them over 5 weeks.

4.2.1a Facilitator input

Psychologists were trained in applying CBT techniques within a physical health context to formulate common cognitive behavioural maintenance patterns as well as utilising motivational interviewing to facilitate behaviour change.

A one-day training workshop consisted of:

- Understanding the physical and psychological issues in COPD
- The challenges of self-management in COPD
- The theory and application of the CBT model for breathlessness, panic and prevention of A&E attendance as well as managing frustration and low mood. In addition, practical role plays were conducted for enhancing skills in:
    - Assessing patients' current psychological status
    - Explaining the interaction between emotions and COPD symptoms
    - Motivation (and barriers) to participation
    - Demonstration of exercises and breathing techniques

4.2.1b Results

- After 12 months, total A&E visits had reduced by 42% in the CM group, compared with a 16% rise in the IB group
- The odds of people in the IB group attending A&E 12 months post-intervention was 1.9 times higher than for the CM group
- Reduction in hospital admissions and bed days were greatest in the CM group
- At 6 months, there were significantly greater improvements in anxiety, depression and dyspnoea in the CM group
- Estimated savings at 12 months were greatest in the CM group, amounting to £30k or £270 per participant

4.2.1c Primary outcome

Health service use Frequency of A&E attendance and frequency and duration of COPD-related hospital admissions.

4.2.1d Secondary outcomes:

Mood and health status were measured at baseline, 6 weeks and 6 months.

4.2.1e Participant feedback

- 78% reported that the CM was very useful, 92% reported more confidence in managing COPD, and 79% reported a great improvement to their quality of life
- most useful aspects were telephone discussions
- managing breathlessness and panic
- distinguishing between anxiety and a flare up
- pacing, breathing and relaxation

Improvements suggested included increasing the programme length as well as combining it with group sessions to increase motivation and social contact. The information booklets were useful. Facilitator input was appreciated and more practical elements were needed in addition to reading information.

- The COPD breathlessness manual (CM) resulted in greater improvements in health-care use, mood and health status, with greater NHS savings, compared to IB
- It appears that IB plus facilitator input is beneficial up to a point, but does not result in long term sustained changes compared to the CBT component underpinning the CM
- Participants in the IB group were almost twice as likely to attend A&E in the 12 months post intervention, compared to participants in the CM group.
- At 12 months, A&E visits in the IB group had increased by 16%. (Most were discharged from A&E in the 12-month follow-up period, indicating potentially avoidable visits, perhaps due to almost a quarter remaining clinically anxious and reporting greater dyspnoea)
- In comparison, A&E visits in the CM group had fallen by 42% along with a greater reduction in anxiety and depression

The results of this study highlight the comparable benefits of delivering CBT in both group and home-based settings. The CM was a targeted intervention and not part of a wider PR or other exercise/education programme. This study highlights that providing no CBT intervention leaves potential for psychological problems to escalate and can lead to inappropriate health-care use and increasing NHS costs. It highlights the importance of intervening early in COPD with brief, targeted, CBT interventions, to prevent the development and worsening of anxiety, panic attacks and panic disorder and associated hospital admissions.

The delivery of the CM intervention, i.e. brief with minimal telephone-based support appears feasible and relates to other studies showing that weekly session and telephone booster sessions of CBT can improve anxiety, depression, mastery and fatigue in COPD and a self-managed programme in primary care offering minimal telephone support can lead to health benefits similar to PR.

The CM is cost-effective and easy to deliver in different settings being potentially beneficial for people with anxiety and depression, frequent GP or A&E attenders, post exacerbation or as an 'add-on' to PR to increase adherence. It could also be implemented within a respiratory service or an Improving Access to Psychological Therapies service in accordance with government policy on addressing mental health in long-term conditions. (Howard, 2010: Howard, 2014)

4.2.2 A four week group CBT breathlessness intervention

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Full title: The effectiveness of a four week group cognitive-behavioural breathlessness intervention on health status, mood and hospital admissions in elderly patients with chronic obstructive pulmonary disease

When this study began, there were no other interventions known about group breathlessness interventions specifically tailored for patients with COPD in the advanced stages of their disease. This study addresses this disparity. This cognitive-behavioural breathlessness multi-disciplinary intervention was a stand-alone intervention, building upon previous breathlessness research in lung cancer as well as CBT studies in COPD. This study assessed the feasibility of the study on:

- health status
- psychological well-being
- accident & emergency (A&E) attendance
- length of hospital stay

It was multidisciplinary using a cognitive-behavioural format to address understanding of:

- COPD and medication
- anxiety, panic and depression
- activity pacing
- relaxation
- breathing retraining
- goal-setting

The intervention comprised four-weekly two-hour sessions. It was based on the self-regulatory model of adjustment to physical illness (Leventhal, et al,1980; Meyer & Nerenz,1980) previously described in previous EBSs and Clark's (1986) cognitive-behavioural model of panic. Central to intervention components was modifying unhelpful and maladaptive illness cognitions and behaviours.

The sessions were interactive and included information on:

- COPD and treatments in the context of identifying illness and treatment beliefs addressing COPD misconceptions and linking with maladaptive coping behaviours
- A cognitive-behavioural model of anxiety and breathlessness, highlighting the interaction of thoughts, feelings, physiological response and behaviours was worked through each week with coping strategies to break the cycle
- Relaxation, breathing techniques, positioning and effective chest clearance techniques and resulting effects on reducing the physiological effects of anxiety were explained and trialled
- Modifying catastrophic cognitions in anxiety and breathlessness and learning to challenge/replace with affirmative statement as well as using distraction techniques to modify behavioural response were key elements to reducing anxiety and panic
- Practising coping strategies such as planning, pacing, problem-solving, energy conservation, goal-setting and learning to respond appropriately to symptoms were aimed at reducing avoidance behaviours maintaining anxiety and low mood, promoting effective self-management and simultaneously shifting illness beliefs and' to more helpful ways of thinking. Weekly homework was given to help consolidate learning such as practising relaxation and breathing techniques, recording breathlessness and related thoughts, feelings, behaviours and physiological responses, increasing activities using goal-setting and pacing and learning to identify and challenge unhelpful thought patterns
- Participants were given a handbook and a relaxation tape to accompany the intervention and were encouraged to practise exercises daily
- A six-week telephone follow-up was undertaken
- All groups received input from the same members of the multidisciplinary team, namely a respiratory CNS, health psychologist, physiotherapist and occupational therapist
- Groups ran consecutively throughout the 12 months (eight groups in total, six participants on average per group

Retrospective data on accident & emergency (A&E) attendances and length of hospital stay was collected six months before and six months after the intervention and the data compared to a matched waiting list control group.

4.2.2a Findings at one year showed:

- significant improvements in depression and health status
- a non-significant improvement in anxiety
- a significant reduction in A&E attendance
- a non-significant reduction in length of hospital stay in the intervention group, compared to comparative increases in the control group, highlighting the cost-effectiveness of the intervention (Howard, et al, 2010).

4.3 Other carer support initiatives

4.3.1 The breathing space clinic

The Breathing Space Clinic is a multi-disciplinary, inter-organisational hospice-based pilot clinic to support the holistic needs of patients with advanced COPD. As discussed above, given that there are currently no reliable means of identifying when COPD patients enter their last year of life, Breathing Space combines the specialist expertise of both COPD-specific and palliative care teams to provide information, non-pharmacological and pharmacological interventions, advance care planning, etc.

This clinic thus aims to maximise quality of life for patients with very severe disease responding to need rather than prognosis.

The Breathing Space Clinic, involved collaboration between the hospice, COPD patients, primary care teams and specialist respiratory teams across three London boroughs. It targets those patients with very severe COPD with complex needs, including those arising from co-morbidities. The referral pathway complies with NICE requirements.

Significant time commitment and multi-disciplinary effort was required to develop the clinic concept to an operational level. Challenges were encountered in developing explicit referral criteria and these will be reviewed in light of the clinic metrics.

4.3.1a Conclusion

Collaborative interventions have potential to greatly improve patient care but require commitment and learning from all involved (Hodson, et al, 2011).

4.3.2 The Breathe Easy support group network

Provides support and information for people living with a lung condition, and for those who look after them. The British Lung Foundation run COPD rehabilitation exercise and support groups across the UK.

British Lung Foundation (BLF) runs local Breathe Easy group meetings

https://www.blf.org.uk/BreatheEasy

4.4 Breathlessness related issues

4.4.1 Obstructive Sleep Apnoea (OSA) pack British Lung Foundation

OSA Pack Part 1 - What is obstructive sleep apnoea? Signs, symptoms and risk factors. Part introduces people lung OSA to the condition and the symptoms associated with the condition.

The booklet includes:

- the cycle of OSA
- how common is OSA?
- who is affected?
- my health questionnaire: http://shop.blf.org.uk/collections/hcp/products/osa-pack-part-one

OSA Pack Part 2 - Do I have obstructive sleep apnoea? What to expect from assessment and diagnosis

Part 2 takes you through the next steps to being diagnosed with OSA and what to expect if referred for clinical assessment.

The booklet includes:

- what to do if you think you have OSA
- my lifestyle
- epworth Sleepiness Scale
- assessment and diagnosis

http://shop.blf.org.uk/collections/hcp/products/osa-pack-part-two-do-i-have-osa

OSA Pack Part 3 - Everything you need to know to help manage your condition.

The final part of the OSA information pack is intended for people who have been diagnosed with OSA.

The booklet includes:

- treatment options

- getting used to treatment
- healthy living and OSA
- driving, travelling and holiday

http://shop.blf.org.uk/collections/osa-hcp/products/osa-pack-part-three-living-with-obstructive-sleep-apnoea

4.4.2 The use of opioids for refractory dyspnoea

There is on-going debate about using opioids long term given their safety in long-term use is not yet established. Caution is now taken because of the impact of chronic opioid use on sleep quality, oxygenation and the incidence of obstructive sleep apnoea. If breathlessness becomes very distressing despite oxygen use, a number of medications are available to reduce the sensation of breathlessness. These include tranquillisers and strong painkillers such as morphine.

A recent national practice guideline recommends the use of opioids for the treatment of refractory dyspnoea in patients with advanced chronic obstructive pulmonary disease (COPD)[19].

  - Patients reported that opioids provided a sense of calm and relief from severe dyspnoea
  - Family caregivers felt that opioids helped patients to breathe more “normally,” observed improvements in patients’ symptoms of anxiety and depression, and experienced reductions in their own stress
  - Patients reported substantial improvements in their quality of life
  - All patients and family caregivers wanted opioid therapy to continue
  - Most physicians however, were reluctant to prescribe opioids for refractory dyspnoea, describing a lack of related knowledge and experience, and fears related to the potential adverse effects and legal censure
  - The discrepancies between the positive experiences of patients and family caregivers and the reluctance of physicians to prescribe opioids for refractory dyspnoea constitute an important gap in care
  - This could be bridged by improving uptake of practice guidelines and to increase doctors’ confidence in prescribing opioids for dyspnoea refractory to conventional treatment (Rocker et al, 2012: Young, et al, 2012).

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[19] *Marciniuk DD, Goodridge D, Hernandez P, et al; Canadian Thoracic Society COPD Committee Dyspnea Expert Working Group. Managing dyspnoea in patients with advanced chronic obstructive pulmonary disease: A Canadian Thoracic Society clinical practice guideline. Can Respir J 2011;18:69-78.*

4.4.3 Non-invasive ventilation (NIV)

Non-Invasive Ventilation (NIV) is a recognised method to support the breathing in a selected group of patients with COPD who consistently show raised levels of carbon dioxide in their blood. It is now widely used for the treatment of respiratory failure occurring during exacerbations of COPD (Huttman, et al, 2014).

NIV for patients needs the support of family carers - those with ‘very supportive’ family having good outcomes. Poor support can affect NIV compliance and subsequent efficacy. Patients’ families can become the first port of call for any NIV-related problems.

NICE Guideline, CG101, recommend that:

- NIV should be used as the treatment of choice for persistent hypercapnic ventilatory failure during exacerbations not responding to medical therapy
- It should be delivered by staff trained in its application, experienced in its use and aware of its limitations
- When patients are started on NIV, there should be a clear plan covering what to do in the event of deterioration and ceilings of therapy should be agreed
- People admitted to hospital with an exacerbation of COPD and with persistent acidotic ventilatory failure[20] are promptly assessed for, and receive, non-invasive ventilation delivered by appropriately trained staff in a dedicated setting[21]

http://www.aquanw.nhs.uk/Downloads/IOP/COPD%20-%20CCG%20reports/COPD%20IOP%20Report.pdf

4.4.3a Carer resource - British Lung Foundation

https://www.blf.org.uk/Page/non-invasive-ventilation-NIV

Coping with the final stages of chronic lung disease - physical care.

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[20] *Although it is difficult to find any data that specifically meets the needs of the patients with persistent acidotic ventilator failure it is still an important indicator of access by COPD patients to NIV as opposed to those COPD patients that receive no ventilation or invasive ventilation.*

[21] *All data here is from: Aqua Analytics (2014)*

4.4.4 Home ventilation

A retrospective study was undertaken with families during the last 3 months of 168 patients who had been under home with mechanical ventilation. Explored the a) awareness of disease, b) family burden, c) dying, and d) medical and technical problems.

Study findings:

- Most patients complaining of respiratory symptoms were aware of the severity and prognosis of the disease.
- Family burden was high especially in relation to the need for money, unrelated to diagnosis and mechanical ventilation
- 78 patients died at home, 70 patients in a medical ward and 20 in ICU
- Families of the patients did not report major technical problems on the use of ventilators

In comparison with mechanical invasively ventilated patients, noninvasively ventilated patients were more aware of prognosis, used more respiratory drugs, changed ventilation time more frequently and died less frequently when under mechanical ventilation (Vitacca, et al, 2010).

4.5 Oxygen therapy

Notwithstanding that oxygen is one of the commonest health-care interventions worldwide, it is misunderstood by many HCPs (Kelly, 2015), and its use can be affected by various attitudes, beliefs and organisational barriers relating to its provision (O'Driscoll, et al, 2015).

Long Term Oxygen Therapy (LTOT) is very beneficial to some COPD patients. However oxygen services are not always directed appropriately. The number of patients receiving oxygen at home in the North West is 16.6 per 10,000 head of population and there may be scope to further improve home oxygen services. Appropriately directed long-term oxygen can improve survival rates by around 40%. Also, 20% of people with COPD would benefit from home oxygen therapy but do not receive it. PCTs that have introduced a review of their oxygen registers coupled with the introduction of a formal assessment service have reduced their annual spend by up to 20%. If this was replicated across England, it is estimated that they could amount to between £10-20m of savings a year (Aqua Analytics 2014).

4.5.1 Carer resources

Coping with the final stages of chronic lung disease - physical care

The "Home Oxygen Booklet - This has been developed by Lung Foundation Australia as a resource for those with a chronic lung condition, who has recently been prescribed home oxygen therapy, or may be prescribed it in the near future.
http://lungfoundation.com.au/home-oxygen-booklet-second-edition/

4.6 NHS and government good practice projects – related to oxygen therapy

4.6.1 COPD Commissioning toolkit – Home Oxygen specification. DH, Aug 2012.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212876/chronic-obstructive-pulmonary-disease-COPD-commissioning-toolkit.pdf

Good Practice for Home Oxygen
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212880/Service-spec-Home-Oxygen-Assessment-and-Review.doc

4.6.2 NHS Improvement - Lung national improvement projects improving home oxygen: testing the case for change

♻ ☀

Home oxygen therapy is provided to about 85,000 people in England, costing approximately £110 million a year. Home oxygen service – assessment and review (HOS-AR) is variable as patients in many Primary Care Trusts (PCTs) do not receive a quality assured clinical assessment and a review of their on-going need for long term home oxygen.

The variation in provision of HOS-AR increases the potential for poor quality care and waste and it has been estimated that 24% to 43% of home oxygen prescribed in England is not used or provides no clinical benefit.

Gross savings of up to 40% - equivalent nationally to £45 million a year or £300,000 per PCT could potentially be achieved through the establishment of home oxygen services, oxygen register review and formal clinical assessment. Reducing variation in service provision can meet goals of The Outcomes Strategy for COPD and Asthma in England.

This project worked with clinical teams across England to:

- support them in identifying, testing and implementing the changes needed to achieve good practice in HOS-AR
- seeking to understand the key components that have the greatest impact on the patient pathway

The primary aims of the project were:

- Locally define and implement the patient's home oxygen care pathway in alignment with the Good Practice Guide national publication
- Identify and reduce variation in the delivery of care
- Test the components of care that led to an effective HOS-AR model
- Identify the success principles that other organisations and teams could learn from and adopt
- Inform future 'prototyping' work
- Patient experience and outcomes were also a focus as was removing waste and duplication
- 9/12 of the oxygen work stream project teams delivered collective prescribing cost efficiencies totalling approximately £640,000

Clinical teams all focussed on specific aims which included:

- Develop accurate registers of patients in receipt of home oxygen therapy
- Utilise the home oxygen service data around initiating prescriber, oxygen consumption, flow rates, patient concordance and therapy modality more effectively and in combination with clinical data about individual patients
- Ensuring all existing and future patients in receipt of home oxygen receive clinical assessment and on-going review in line with best practice
- Improve care for non-respiratory patients in receipt of oxygen by better collaborative working with non-respiratory specialists
- Rationalise prescribing of home oxygen to reflects the clinical need of the local population
- Control home oxygen therapy costs
- Develop and implement effective risk assessment and health and safety procedures
- Achieve greater integration of assessment and review services within wider care pathway

Actions for future initiatives were defined:

- Future 'prototyping' will include work that focuses on the delivery of a number of products
- Home oxygen services assessment and review resource hub
- Safe use of oxygen support package

4.6.3 Spread framework for home oxygen service

Project sites and titles included:

- Wirral University Hospital NHS Foundation Trust and NHS Wirral Integrated Community Oxygen Service
- NHS Hull and the City Health Care Partnership. Home Oxygen Service Improvement Project
- Royal Free Hospital NHS Trust, NHS Waltham Forest & North East London, North Central London and Essex Health Innovation Education Cluster (NECLES HIEC). The feasibility and impact of withdrawal of Short Burst Oxygen Therapy (SBOT)
  NHS Nottinghamshire County Community COPD Team, Sherwood Forest Hospitals NHS Foundation Trust and County Health Partnership. Home oxygen – improving quality of care
- NHS Sheffield and Sheffield Teaching Hospitals, NHS Foundation Trust. Home oxygen service improvement project
- NHS Blackpool and Blackpool Teaching Hospitals NHS Foundation Trust. Improving oxygen services and the prescribing of oxygen across NHS Blackpool
- NHS South Staffordshire. Improving home oxygen services through pathway redesign
- Milton Keynes PCT Community Services and Milton Keynes Hospital NHS Foundation Trust. Sustaining the efficiency and effectiveness of the Milton Keynes Home Oxygen Service – Assessment and Review (HOS-AR)

Each project site working on a different part of the home oxygen pathway, produced a number of key themes have emerged which have enabled the development of six top tips for improving home oxygen services:

1. Provide oxygen assessment and review staff with access to supplier data and support in its effective use
2. Use clinical and supplier data systematically to support appropriate prescribing, clinical assessment with on-going review and tight cost control
3. Integrate your oxygen service within the wider respiratory pathway and coordinate activities with non-respiratory specialties
4. Promote the message that ‘home oxygen is a treatment for chronic hypoxemia and NOT a treatment for breathlessness’
5. Work collaboratively to formalise policies and procedures around the safe use of home oxygen
6. Establish on-going and effective communication between the oxygen team, primary and secondary care to ensure appropriate prescribing, appropriate referrals and continuous education for patients and professionals[22]

For details of all projects please go to:
http://webarchive.nationalarchives.gov.uk/20130221101407/http:/www.improvement.nhs.uk/documents/Oxygen_Case_for_Change.pdf

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[22] *Précised from Introduction, The Case for change: the current position for home oxygen services in England*

5. Additional EoL issues

5.1 Patient anxiety & depression

Evidence shows disproportionately high prevalence rates of generalised anxiety disorder, panic and depression in COPD compared to the general population as well as other long-term illnesses. Its presence has been associated with greater restrictions on mobility and energy, difficulties with activities of daily living, greater dependence on others for care, lower levels of self-efficacy, impaired functional status and less effective self- management. Serious implications can result from psychological difficulties in COPD including reduced survival, lower quality of life, and reduced physical and social functioning, increased use of health care resources and are associated with unhealthy behaviours such as smoking management (Howard, et al, 2010).

- Anxiety is a significant predictor of the frequency of hospital admissions, readmissions for acute COPD exacerbations and impaired quality of life
- Untreated, co-morbid anxiety can seriously challenge the coping strategies of patients with COPD and their family caregivers
- The available evidence for pharmacological management of anxiety is inconclusive
- Non-pharmacological interventions for managing anxiety and dyspnoea in patients with COPD are indicated
- Worsening dyspnoea can lead to acute anxiety (Al-Gamal & Yorke, 2013).

5.1.1 Interventions for depression: Newcastle COPD CBT care study

Cognitive–behavioural therapy (CBT), including psycho educative initiatives, has been shown to be effective in treating anxiety and has demonstrated effectiveness for adults with COPD. By teaching patients valuable and enduring skills to cope with their dyspnoea and anxiety, it is hoped to ensure a lasting effect that extends beyond treatment completion. (Health Quality Ontario, 2015; Bove, et al, 2015; Smith, et al, 2014).

The Newcastle Chronic Obstructive Pulmonary Disease Cognitive Behavioural Therapy Study is currently testing the Effectiveness of CBT interventions for anxiety in patients with COPD.

This is a prospective open randomised controlled trial comparing CBT with self-help leaflets. The primary outcome measure is the Hospital Anxiety & Depression Scale (HADS) – anxiety subscale. Secondary outcome measures include disease specific quality of life COPD Assessment Tool (CAT), generic quality of life (EQ5D) and HADS depression subscale. Patients will be followed up at three, six and 12 months following randomisation.

This is the first randomised controlled trial to evaluate the use of cognitive behavioural therapy undertaken by respiratory nurses. Recruitment was planned to be completed by February 2014.

The study intervention involves standard care plus a brief CBT based program delivered by respiratory nurses. Clear manualised treatment will be used to ensure the CBT based treatment can be replicated. A manualised protocol has been specifically developed for this study by the Respiratory Nurse & Consultant Psychologist. The CBT will be delivered by four respiratory Nurses. The intervention will be delivered to individual patients in either in a respiratory clinic in secondary care or within the patients' home. The intervention is tailored to the patient's individual needs (within the boundaries of the manual).

Patients will be offered between two to six sessions of therapy as required. The number of sessions will be based on the patient's progress and HADS scores. The initial session will take 30–60 minutes. Subsequent follow up sessions will take up to 30 minutes.

The intervention includes the following processes:

- The nurse assesses the patient's reported current difficulties and develops an individualised treatment plan
- The treatment plan may include the development of coping strategies including goal-setting, identifying, challenging and changing negative thoughts, distraction, breathing control, problem-solving, activity scheduling/diary, relaxation, weighing up pros and cons; positive logs, learning to respond appropriately to symptoms and reducing avoidance and safety behaviours that maintain anxiety and low mood (Heslop, et al, 2013).

5.2 Exacerbations

Exacerbation: "an event in the natural course of the disease characterised by a change in the patient's baseline dyspnoea, cough and/or sputum that is beyond normal day-to-day variations, is acute in onset and may warrant a change in medication in a patient with underlying COPD"

http://www.who.int/respiratory/copd/GOLD_WR_06.pdf

The two top causes of exacerbations are known to be infection and changes in air quality/air pollution. It is known that many exacerbations are secondary to not following a drug regime correctly, for example the misuse of an inhaler. However in one third of cases the cause is unknown, although many hypothesise it may be due to stress or anxiety (Ward et al, 2014).

NHS analysis has shown that:

- More work needs to be done to quantify the number of patients offered a comprehensive clinical and psychosocial assessment
- Self-management education, action plans and rescue medication packs should be given to COPD patients

Prompt treatment at the onset of exacerbation of symptoms can result in less lung damage, faster recovery, fewer admissions and re-admissions to hospital and improved outcomes. Thus it is important that people who develop exacerbations and their carers are able to understand and recognise exacerbation symptoms.

Predictive risk tools and registers together with tele-monitoring and tele-medicine should help identify those at high risk.(AQuA Analytics 2014).

The DH advises that Commissioners should consider:

- Proactive chronic disease management in primary and community care, including clear action plans, optimisation of therapy, support for self-management, home provision of standby medication, and referral for pulmonary rehabilitation when indicated
- Prompt support for people when they develop new or worsening symptoms, with access to specialist-led care in the community when appropriate
- Early discharge schemes and hospital at home services commissioned to support evidence-based admission avoidance
- Reviewing discharges to identify patients who suffer frequent exacerbations and who need more proactive management (Department of Health, 2012)

NICE recommendation - The impact of exacerbations should be minimised by:

- Giving self-management advice on responding promptly to the symptoms of an exacerbation
- Starting appropriate treatment with oral steroids and/or antibiotics, use of non-invasive ventilation when indicated
- Use of hospital-at-home or assisted-discharge schemes

There is, to date, insufficient data to make firm recommendations about which patients with an exacerbation are most suitable for hospital-at-home or early discharge.

Patient selection should depend on the resources available and absence of factors associated with a worse prognosis, for example, acidosis.

People who have had an exacerbation of COPD are provided with individualised written advice on early recognition of future exacerbations, management strategies (including appropriate provision of antibiotics and corticosteroids for self-treatment at home) and a named contact.

People admitted to hospital with an exacerbation of COPD and with persistent acidotic ventilatory failure are promptly assessed for, and receive, non-invasive ventilation delivered by appropriately trained staff in a dedicated setting (Aqua Analytics, 2014).

5.3 Hospital admissions & discharges

Across the North West there is a higher incidence of people with COPD being readmitted as emergencies (more than two times annually) and considerable variation across the CCGs. Nationally approximately 4.5% of COPD patients die in hospital. On average patients with a COPD diagnosis who die in hospital will have a length of stay of just over 8 days (Aqua Analytics, 2014).

Manchester and Salford have high rates for both mortality and years of life lost. This means that, not only are more people dying but they are dying from COPD at a younger age. Compared to England the North West has a higher number of COPD deaths in hospital. Emergency admission rates for COPD in the North West are increasing and are higher than the England average.

NICE recommend:

- People admitted to hospital with an exacerbation of COPD are reviewed within 2 weeks of discharge
- People admitted to hospital with an exacerbation of COPD are cared for by a respiratory team, and have access to a specialist early supported-discharge scheme with appropriate community support (Aqua Analytics, 2014).

5.3.1 Discharge

Patients discharged from hospital following an exacerbation of COPD often have high levels of depression (64%), anxiety (40%) and uncertainty that drives help-seeking behaviour; 30% are likely to be readmitted within a three-month period. Thus consideration of support at home is an important part of discharge planning. It is important that people who have been admitted to hospital have early and regular follow-up with a review of their COPD, co-existing conditions and psychosocial needs. National guidance recommends that hospital discharge procedures should ensure that patients are offered:

- Smoking cessation support
- Pulmonary rehabilitation referral
- Support for self-management

In addition, NICE Guidance CG101 also supports discharge planning that involves an assessment of the patients fitness for discharge and assessment of their needs once back in the community. Specifically, it recommends:

- Spirometry should be measured in all patients before discharge
- Patients should be re-established on their optimal maintenance bronchodilator therapy before discharge
- Patients who have had an episode of respiratory failure should have satisfactory oximetry or arterial blood gas results before discharge
- All aspects of the routine care that patients receive (including appropriateness and risk of side effects) should be assessed before discharge
- Patients (or home carers) should be given appropriate information to enable them to fully understand the correct use of medications, including oxygen, before discharge
- Arrangements for follow-up and home care (such as visiting nurse, oxygen delivery, referral for other support) should be made before discharge
- Before the patient is discharged, the patient, family and physician should be confident that he or she can manage successfully. When there is remaining doubt a formal activities of daily living assessment may be helpful

5.3.2 Early supported discharge schemes

COPD is the fifth most common cause of emergency re-admission and, across the North West, 13% of COPD patients are readmitted for COPD within 28 days. Aqua Analytics’ recent analysis shows a North West rate of 9.7%, is only 0.7% above the England average however. The National COPD Audit found that nationally, approximately 25% of hospitals had no Early Supported Discharge Scheme despite the fact that early discharge schemes or hospital at home are known to prevent hospital re-admissions (Aqua Analytics, 2014).

5.3.3 Transferring from hospital to home. (December 2015 - NICE guideline)

This new guideline focuses on what should happen in hospital, from admission onwards and throughout someone’s stay, so that their discharge isn’t rushed or unplanned. The guideline, developed by the NICE Collaborating Centre for Social Care - a partnership led by SCIE, ensures people with social care needs get the support they need to leave hospital and prevent delayed discharge from care. SCIE is keen to encourage good collaboration between health and social care. People’s experience of transition between hospital and home is a key indicator on how well integration is working.

- Transition between inpatient hospital settings and community or care home settings for adults with social care needs
- SCIE's integration resources and consultancy services
- NICE Collaborating Centre for Social Care

http://www.scie.org.uk/news/?utm_campaign=6367467_SCIE%20E%20Bulletin%2001%20dec%2015&utm_medium=email&utm_source=SCIE&utm_sfid=003G000002FF4txIAD&utm_role=&dm_i=4O5,3SH63,KSTGKS,DNNK2,1

5.3.4 Carer resource. “Going home from hospital”

A handy guide of things to think about when you are discharged after a flare up of chronic obstructive pulmonary disease (NHS, 2012). Patients with a history of exacerbations and more severe disease may potentially experience exacerbations with increased frequency, and that exacerbations may be associated with a high risk of death, even after discharge.

http://shop.blf.org.uk/products/going-home-from-hospital

5.3.5 Sleep

Carers should be aware that there are assessments and measurements of sleep disorders available for HCPs to use in a clinical setting. (Garrow, et al, 2014)

5.4 Moving and handling issues for carers

HF patients who experience impaired cognition and reduced functional capacity due to exertional shortness of breath and persistent fatigue will rely on family members to assist with performing self-care behaviours including personal hygiene and elimination (Nauser, et al, 2011).

5.4.1 Patient/carer resources

Coping with the final stages of chronic lung disease - physical care.

5.4.1a ‘Information, training or education’ in strategies for safe moving and handling of the patient.

Hospice UK.
http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers

5.4.1b Macmillan: Hello and how are You? A guide for carers by carers. Book sections on:

- Moving and handling
- Organising equipment and transport
- Personal Care

http://be.macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf

5.4.1c Princess Royal Trust for Carers (PRTC)

Moving and handling http://www.prtlcc.org.uk/en-us/courses/courses-movinghandling.aspx

5.4.1d Marie Curie – film guides

- Helping a person to wash
- Helping with mouth care
- Making a person comfortable in bed
- Rolling a person in bed
- Helping a person take medication
- Helping a person to relax

www.mariecurie.org.uk/filmguides

6. COPD Specific carer support interventions

Interventions to support family carers are scarce. Three only which include family carers in disease management interventions for patients with COPD have been reported in a recent review, two of these being within the date scope of the EBS. One was a feasibility study on home based palliative care; The COPD IMPACT study (Horton, et al, 2013) see below. The other involved carers in Pulmonary Rehabilitation, the experience of a multidisciplinary programme of pulmonary rehabilitation in primary health care from the next of kin's perspective (Zakrisson, et al, 2013), see below page 91. An additional one was identified – the "Inspired" self-management outreach programme for patients and carers (Young J, et al, 2012) see page 84. Descriptions of these studies follow.

6.1 Palliative care introduction

Palliative Care. *'an approach that improves the quality of life of patients and their families facing the problems 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.'*[1]

"care for people of all ages with a life limiting condition"[1]

"Palliative" comes the Latin word "palliare" meaning to cloak. Thus, the aim of palliative care is to cloak i.e. wrap care around those with advanced disease and their carers. Palliative care looks to address physical, emotional, spiritual and social concerns of patients who have advanced illnesses and those around them". Palliative care being a specialist branch of healthcare that, rather than focusing on active interventions and treatments intended to prolong life, it focuses instead on symptom relief and support to manage the stress and impact of serious illness for someone with a life limiting illness (this being a patient in the last 6 – 12 months of life). Increasingly, more patients are being referred to palliative care services earlier and it is important to remember that palliative care and hospices are not just for those who have cancer (Ward et al, 2014).

Patients with advanced COPD need palliation of symptoms, such as breathlessness and anxiety, throughout the long duration of their illness (Momen, et al, 2012). Both Palliative care (PC) – and Pulmonary Rehabilitation (PR) - are important components of the integrated care of the COPD patient. The goal of both interventions is to relieve symptoms and improve functional status and components of both of them should be an integral part of medical care for COPD. They are both underused, however, and often offered too late in the disease trajectory (Reticker, et al, 2012).

Oishi and Murtagh (2014) looked at PC in non-cancer patients, particularly COPD, their review concluding that many people who want to be cared for at home whilst dying, die without enough access to this care. Many PC needs can be managed by GPs or respiratory specialists and primary care has the potential to fulfil patient and carer hopes and needs by playing a central role in providing this care (Oishi & Murtagh, 2014; Beernaert, et al, 2013). At present, the roles of professionals are unclear to patients, carers and HCPs themselves and this lack of collaboration between health-care professionals constitute barriers to effective care. In order to provide better palliative care provision to non-cancer patients in the community, effective interprofessional coordinated working is necessary in this context to deal with HCP and patient/carer expectations and conflicts. Who should coordinate this care and what a model would look like would need to be explored further (Oishi & Murtagh, 2014).

A systematic review examining the unmet needs of home based palliative care patients and carers showed that, whilst physical care needs were met, psychosocial needs were neglected. If PC is going to be home based, the implications for practice are that standards of care across palliative home based care settings may need to be considered and a more holistic focus adopted in order to meet these needs (Ventura, et al, 2014).

Despite the World Health Organisation calling for palliative care for all chronic life-limiting diseases, Beermart's 2015 study showed that PC services still serve mainly cancer patients. This may be due to an historical focus on cancer, and the easier predictability of its disease trajectory. Another explanation is, as discussed above, that COPD is seen by many patients and caregivers as being a way of life rather than an illness, not life threatening or appropriate for PC. People with COPD are much less likely to be referred to a PC service than patients with heart failure, severe dementia or cancer. This is despite COPD having similar disease symptoms and a trajectory comparable to heart failure, an unpredictable prognosis similar to dementia, and similar PC needs to those with cancer such as pain, feelings of drowsiness, sadness, nervousness and difficulties breathing in the last week of life (Beernaert, et al, 2015).

Patients with COPD more often receive treatment with a curative or life-prolonging goal and are less likely than those with other chronic life-limiting diseases to receive generalist treatment with a palliative or comfort intent. Even when treatment is not primarily curative or life-prolonging, the absence of noninvasive ventilation in many PC settings, as opposed to in pulmonology wards can result in physicians not considering PC referrals for COPD patients. The other reason for COPD patients not being referred for PC care is, as discussed elsewhere, PC is still seen mainly as terminal care. When COPD patients are referred, half of them are referred less than 10 to 20 days before death - considerably shorter than for cancer patients and a time period which may not be enough to achieve the goals of PC. People with COPD receive palliative care less often than those with other chronic life-limiting diseases, both in terms of referral to specialist PC services and in terms of receiving generalist care aimed at comfort. An increasing awareness of PC services as an option for COPD patients is needed and it is important that PC expertise and knowledge is cascaded to professional groups such as GPs and respiratory physicians. In this way, combining skills and cooperation, COPD care could be improved (Beermart, et al, 2013; 2015).

Thus COPD patients have many unmet palliative care (PC) needs (White, et al, 2011). Hospitalisation for acute exacerbation increases subsequent mortality risk and as the disease progresses it demands a more PC approach . However, a main barrier to providing quality PC in COPD is the unpredictable disease trajectory (Oishi & Murtagh, 2014; Duenke, et al, 2014) which makes it difficult to predict how long patients will survive and thus when PC services might be helpful to them (Horton, et al, 2013). This difficulty is exacerbated by patients' limited understanding of treatment options, and communication barriers between patients and health care professionals (Horton, et al, 2013; Oishi & Murtagh, 2014). This lack of effective communication with health-care professionals negatively impacts on the care received by patients and carers (Ventura, et al, 2014).

The term, "Palliative Care" has the negative connotations of End Stage Care and for COPD patients and this can impede their engagement with this concept (Duenke, et al, 2014). This can result in many patients in the advanced stages of COPD being housebound, they and their caregivers receiving little support from traditional community health services. Several professional societies (including the American Thoracic Society (ATS), the Canadian Thoracic Society (CTS), and the American College of Chest Physicians (ACCP) - have called for greater involvement from palliative care service providers in this setting (Horton, et al, 2013).

Despite the new definition of palliative care In 2002 by the World Health Organization (which meant that palliative care should not be limited to the terminal phase of an illness and can be delivered beside curative care to patients with any life-threatening illness including COPD), a proactive approach to issues arising in End Stage COPD is not common for these patients, even though the symptoms that occur in the end stage of COPD can be very severe (Duenke, et al, 2014; White, et al, 2011). There does not appear to be a formalised palliative care approach to COPD patients and they have less universal access to specialist palliative care services than those with malignant lung diseases. They receive less opioids and benzodiazepines than patients with lung cancer and die more often in Intensive Care Units (ICU) (Duenke, et al, 2014).

As their disease worsens, COPD patients need to know about their prognosis, their risk of death, and about future treatment available for optimum treatment of symptoms, in order to be able to choose what and where they receive this care. White's study showed that the palliative care needs of COPD patients were to control symptoms, especially breathlessness. Despite the severity of their disease, only 30% study participants were on suboptimal treatment and more than half had never been referred to pulmonary rehabilitation. 30% of these advanced COPD sufferers had not been admitted to hospital in the previous 2 years. From these findings it is evident that not all severely affected people with COPD were receiving active treatment (White, et al, 2011).

It is important for patients to die a dignified death and family carers have identified that clear explanations by doctors of treatment options during the final months of life are important for this to be enabled (Isis, et al, 2013).

Given there it is difficult to identify a ‘right time’ in a COPD patient’s journey when they should be referred to palliative care services, the value of palliative care in conjunction with active medical treatment is being recognised (Ward, et al, 2014). Addressing the need for proactive care when an acute exacerbation COPD (AECOPD) takes place, may be a good opportunity to identify patients at high risk of subsequent readmission or post-discharge mortality and hence who can benefit from the proactive palliative care approach advocated by WHO. Following an AECOPD more care may be required to support the patient and family (Duenke, 2014). Although COPD patients know they may die from their disease, death is often not imminent and not specifically signalled by breathlessness. Thus palliation of breathlessness in advanced COPD appears more important for patients than considering their EoL care (White, et al, 2011).

6.2 Home based palliative care COPD IMPACT study

An evaluation of the feasibility of implementing a home-based palliative care service for patients with advanced COPD and their carers. There was a customised palliative care intervention aimed at meeting previously unmet needs of patients and carers. Outcomes were evaluated within a feasibility framework (Horton, et al, 2013).

This study and its innovative approaches to palliation has long been a research focus for this team. In order to incorporate quality indicators within a multidisciplinary approach, their PC programme has shifted from a traditional focus on malignant disease to one which attempts to provide care to COPD patients. It implements a comprehensive home-based palliative care intervention specifically customised to address the needs of those living with advanced COPD.

A new aspect was the integration of chronic disease management strategies with education on disease prognosis/end-of life decision making along with concurrent proactive provision of comprehensive home-based multidisciplinary palliative care. This has now informed a new clinical service in which inpatients with advanced COPD and high needs are identified. Shorter, focused, and relevant education sessions are provided according to need, supplemented by advance care planning sessions in the home.

Using a mixed-methods evaluation approach there has been a dramatic drop in ER visits and hospitalisations the years before and after enrolment.

The COPD IMPACT was an attempt to provide a coordinated, customised palliative care intervention to patients with non-malignant disease. The feasibility of evaluating related outcomes for patients with advanced COPD patients with advanced disease was challenging in that COPD patients often struggle to attend ambulatory clinics and therein lay difficulties inherent in carrying out studies in patients who are living with multiple burdens of advanced disease.

Table 3. Home based palliative care: COPD impact study

	Components of intervention	**Intervention facilitated by**
Intervention. Part A. COPD self-management educational program based on the Living Well with COPD program plus the eighth educational module on EOL care and decision making delivered in the patient's home over four to eight weeks.	Educational material (eight modules) 1. Basic information about COPD Breathing and coughing techniques Energy conservation and relaxation exercises 2.Preventing and controlling symptoms through inhalation technique 3. Recognition of and initiating a plan of action for an acute exacerbation 4. Adopting a healthy lifestyle 5. Leisure and traveling 6. A home exercise program 7. Understanding indications and implications of long-term home oxygen therapy 8. End of Life care/decision making	Trained COPD educator
Comprehensive palliative care consultation within four weeks of completing educational component.	Assessment of (1) current symptoms (2) understanding of illness (3) goals of care (4) impact of the illness on each of physical, social, psychological, and spiritual well-being. Formulation of individualised treatment plan with specific recommendations regarding symptom treatment and coordination of additional supportive care services forwarded to family physician in	Palliative care doctor and registered nurse

	writing within 48 hours of the consult.	
Intervention Part b Establish common medical chart in the home to facilitate coordinated care and sharing of information between various caregivers.	The Home Chart for the Integrated Palliative Care Service includes: (1) comprehensive palliative care assessment (2) Dr's orders/standing orders (3) medication list (4) care plans and flow sheets (5) multidisciplinary progress notes (6) home support (7) consent forms	Palliative care RN or continuing care coordinator
On-going case management.	(1) Weekly telephone contact with the patients and or caregiver to assess overall well-being (2) Follow-up home visits as needed to address changes in status (3) Coordination of services and liaison with the palliative care physician, family physician, and community-based continuing care nurses (4) Palliative care MD reassessment of treatment at home as required by changes in clinical status	Palliative care MD and RN

6.2.1 Findings

These are not the full findings but those which illustrate best the most significant of these for the purposes of this EBS.

Patient and caregiver satisfaction:

- The involvement of the palliative care team was welcomed and valued by both
- Carers' involvement was welcomed and valued. They stressed the importance of obtaining knowledge and support from the palliative care team
- 80% of enrolled patients readily accepted home-based education and treatments and follow-up by the palliative care team
- There was no significant difference in HRQoL or caregiver burden from baseline to four months. Dyspnoea was the most prevalent and severe symptom, noted by all patients (with a mean severity score of 5.13/10 on the ESAS)
- Tiredness and decline in overall well-being were the next most common symptoms
- Symptom severity remained unchanged over the course of the intervention

EOL outcomes:

- Overall, 56% of the deaths occurred in an acute care setting
- Of three patients (10%) who completed the study three died of end-stage COPD and were admitted to a hospital palliative care unit in the last days because of caregiver exhaustion and inability to cope with symptoms of terminal dyspnoea and delirium
- Although half of all deaths occurred in an acute care setting, none of the patients were intubated or were admitted to an ICU and all had established comfort-focused care plans

None of the deaths occurred at home despite the majority of patients having previously established comfort-based goals of care and the availability of local home-based expertise in palliative care.

Health Care Utilisation

- There were 43 emergency room presentations in 15 patients, 29 of which were directly related to COPD. (Four patients accounting for 62% of these presentations)
- Most patients and carers found it acceptable to complete multiple questionnaires
- Of these their burden scores were low

It became apparent that:

- Housebound dyspnoeic patients had significant primary care/community-based needs, which could not be met when they lacked access to a primary care physician who would see them at home
- Patients and carers often relied on the emergency room to deal with any escalating symptoms or decreased capacity to cope
- Patients require individualised interventions (although all received a minimum set of core interventions in this study)
- Reasons for forgoing intubation and mechanical ventilation and admission to the ICU could not be fully established

6.2.2 Conclusion

Providing home-based palliative care services for patients with advanced COPD is feasible. The stability in HRQoL, caregiver burden, and symptom intensity over the course of the intervention indicates its efficacy. Carefully assessing current palliative care service models can provide important insights and opportunities for local program innovation and evaluation aimed at improving care for those living with advanced COPD (Horton R., et al, 2013).

6.3 “INSPIRED” palliative outreach programme for patients and carers

“Implementing a Novel and Supportive Program of Individualized Care for patients and families living with Respiratory Disease” Accreditation Canada 'Leading Practice' designation as a noteworthy example of high-quality leadership and service delivery in COPD care.

INSPIRED is a customised home-based palliative care service/intervention for patients and caregivers living with advanced COPD and their carers aimed at meeting the needs previously identified by patients and caregivers living with advanced COPD. It is run in partnership with The Canadian Foundation for Healthcare Improvement (CFHI) and Boehringer Ingelheim (Canada) Ltd., at the Queen Elizabeth II Health Sciences Centre in Halifax, Nova Scotia. Canada. It has reduced by 60% emergency department (ED) visits, hospital admissions and days in hospital.

Chronic obstructive pulmonary disease is the fourth leading cause of death in Canada and a major driver of hospital visits. A quarter (25%) of Canadians over the age of 35 can expect to be diagnosed with the disease at some point in their life, and the number of people living with COPD is rising. COPD is a primary cause of emergency room (ER) and hospital visits in Canada, and patients with AECOPD accounted for approximately 300 admissions a year in Canada, with an average length of stay of 10 days, costing $3-million annually in inpatient bed costs. A typical scenario for a person living with moderate to severe COPD involves arriving at the ED in crisis, severely short of breath (i.e., an ‘acute exacerbation of COPD or AECOPD) which results in a lengthy hospital stay. When home again and lacking early follow-up and with no plan for the next AECOPD, this cycle repeats itself. The medical, psychosocial and spiritual care needs of patients and their families are not addressed in a patient-centred, evidence-informed and cost-effective way which causes anxiety resulting in high healthcare costs and visits

INSPIRED takes a proactive approach to caring for patients living with advanced COPD and their families. The Clinical team–involves:

- a respirologist/pulmonologist
- registered respiratory therapists (RRT)
- spiritual care practitioner (SCP)
- program coordinator

By responding to the underlying and unmet needs of patients and families living with moderate to severe COPD, INSPIRED delivers more holistic and individualised patient care, supports family caregivers and reduces reliance on hospital-based care. It fills in gaps in care that underlie the COPD (and chronic disease) care challenge offering:

- hospital-to-home outreach – including home visits and access to a telephone ‘hotline’
- patients and their families self-management education, confidence building and an action plan to guide treatment choices at home
- psychosocial and spiritual care support and access to advance care planning

6.3.1 Measurement

Measures for the efficacy of the programme include:

- ER visits
- Hospital admissions
- Acute inpatient length of stay (LOS)
- Efficiency (cost containment)
- Care Transitions Measure (CTM®)
- Quality of life, anxiety/depression and hope
- Program helpfulness
- Intensive/Intermediate care unit
- (ICU/IMCU) use
- Personal directive (PD) made
- Palliative Care use

Measurements included: Health-related quality of life (HRQoL), caregiver burden, symptom severity, patient/caregiver satisfaction, utilisation of acute care services, EoL outcomes (Horton, et al, 2013)

The strategy for change in INSPIRE concentrates on delivering more holistic patient-centred care while reducing reliance on hospital care. The process involves:

- Patients with COPD (Medical Research Council stage 4-5) are referred to INSPIRED by inpatient staff
- The INSPIRED respirologist and RRT meet with the patient to seek program enrolment, optimize medications* and develop an action plan[23].
- The patient is discharged and the RRT phones within 48-72 hrs to arrange the first home visit

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[23] *as per American Thoracic Society Documents (2008).*

- The RRT and SCP make home visits ~2 weeks apart (~4-6 weeks). The RRT provides self-management education and reviews the action plan. The SCP then assesses coping and reviews goals of care, as needed, including ACP (completing a PD if the patient so desires)
- Monthly phone follow-up continues for 3 months; and additional follow-up, as needed

6.3.2 Results

Compared to six months pre-INSPIRED, for n=131 patients there were:

- 60% fewer ER visits
- 63% fewer hospital admission (patients admitted 2X or more in six months decreased)
- 62% fewer days in hospital (an estimated indirect cost ‘saving’ of $977,000 (more than 3X annual INSPIRED operating costs)
- These reductions continued for n=93 patients compared to 12 months pre-INSPIRED

HRQoL, caregiver burden and symptom severity did not change (McDonald & Khor, 2013; Horton, et al, 2013).

Interviews with patients showed that they felt:

- more confidence in managing their symptoms and willing to discuss goals of care, including ACP
- less anxious
- significant improvements in quality of care transitions
- no marked changes in quality of life, anxiety/depression and hope

Patients and carers report on how INSPIRED helped them by offering:

- Action plans and prescriptions on-hand or on-order
- Accessible education, information and resources
- Improved outcomes relevant to patient and family, for example, less breathlessness
- more stamina, recognition and management of COPD, use of medications
- Someone to call for guidance and support; and not feeling so alone and abandoned
- Feeling cared for by caring, reliable, knowledgeable staff using effective communication
- Patients at end-of-life showed significantly lower LOS and greater likelihood to have PDs also significantly improved

6.3.3 INSPIRED intervention components

Intervention conducted by COPD self-management educational program based on the Living Well with COPD program[24] plus the eighth educational module on EOL care and decision[25] delivered in the patient's home over four to eight weeks (please see table x for more information).

6.3.4 Comments on INSPIRED

- Peer reviewed evidence showed that home based education and treatments and follow-up by the palliative care team were welcomed by COPD patients and their families. However, family caregivers of COPD patients have a very onerous task and are often physically and emotionally exhausted from years of stress and fatigue associated with care giving on the COPD rollercoaster. Even with the best available supports, dying at home from end-stage COPD may not be realistic or even the best option for many.
- For those who survived the period of this study, it became increasingly clear that housebound dyspnoeic patients had significant primary care/community-based needs, which could not be met when they lacked access to a primary care physician who would see them at home. Patients still often relied on the emergency room to deal with any escalating symptoms or decreased capacity to cope.
- Standardising the intervention is an issue. Some patients need multiple home visits; others simply required telephone support and coordinated services. A minimum set of core interventions were established, but it is not possible or desirable to standardise all aspects of palliative care involvement for any individual patient dyads. According to need, this study provided shorter, focused, and relevant education sessions, supplemented by advance care planning sessions in the home.
- The palliative care program shifted from its traditional focus on malignant disease to the COPD population and builds upon others on chronic illness by implementing a comprehensive home-based palliative care intervention specifically customised to address the needs of those living with advanced COPD.
- A new aspect covered in the study was the integration of chronic disease management strategies with education on disease prognosis/end-of life decision making along with concurrent proactive provision of comprehensive home-based multidisciplinary palliative care.

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[24] *Based on; Bourbeau J, Julien M, Maltais F, Rouleau M, Beaupre A, Begin R, et al, (2003). Reduction of hospital utilisation in patients with chronic obstructive pulmonary disease: A disease specific self-management intervention. Arch Intern Med,163, 5:585–591.*

[25] *Based on: Wilson KG, Aaron SD, Vandemheen KL, Hebert PC, McKim DA, Fiset V, et al, (2005). Evaluation of a decision aid for making choices about intubation and mechanical ventilation in chronic obstructive pulmonary disease. Patient Educ Couns, 57, 1,:88–95.*

Table 4 INSPIRED intervention components

Education	Modules and Contents	Trainer
	1. Basic information about COPD, i.e., breathing and coughing techniques, energy conservation and relaxation exercises 2. Preventing and controlling symptoms through inhalation technique 3. Recognition of and initiating a plan of action for an acute exacerbation 4. Adopting a healthy lifestyle 5. Leisure and traveling 6. A home exercise program 7. Understanding indications and implications of long-term home oxygen therapy 8. End of Life Care/decision making [26]	Trained COPD educator
Comprehensive palliative care consultation	To be undertaken within four weeks of completing the educational component. Assessment of: • current symptoms • understanding of illness • goals of care • the impact of the illness on physical, social, psychological, and spiritual well-being Formulation of individualised treatment plan with specific recommendations regarding symptom treatment and coordination of additional supportive care services. To be forwarded to family physician in writing within 48 hours of the consult.	Palliative care MD and RN
Establish common home medical chart	To facilitate coordinated care and sharing of information between various caregivers The Home Chart for the Integrated Palliative Care Service includes: • Comprehensive Palliative Care Assessment • Dr's orders / standing orders • Medication List	Palliative care RN or continuing care coordinator

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[26] *This module had undergone prior evaluation in a cohort of patients attending the Pulmonary Rehabilitation Program in Halifax.*

	• Care plans and flow sheets • Multidisciplinary progress notes • Home support • Consent forms	
Ongoing case management	1. Weekly telephone contact with the patients and or caregiver to assess overall well-being. 2. Follow-up home visits as needed to address changes in status 3. Coordination of services and liaison with the palliative care physician, family physician, and community-based continuing care nurses 4. Palliative care MD reassessment of treatment at home as required by changes in clinical status	Palliative care MD and RN
Follow up	After completion of the education program, patients were followed at home by the Capital Health Integrated Palliative Care Service for a period of four months. All participants were initially seen together by a palliative care nurse case manager and consultant physician who completed a comprehensive individualised palliative care assessment and treatment plan which was forwarded in writing to the patient's primary care physician. The nurse case manager: • Continued regular weekly follow-up by phone • Co-ordinated delivery of additional home support services customised to individual need • Made unscheduled follow-up visits if there was a need for reassessment based on a change in status • Co-ordinated physician/nurse manager joint/individual home visits when necessary and depending on the clinical situation • Provided all patients with contact information for the nurse case manager and for afterhours support by the on-call palliative care physician • Reviewed all patients at weekly multidisciplinary team rounds to facilitate coordinated care between the consultant and primary care members of the team HORTON	

Although it had already been seen that providing home-based palliative care services for patients with advanced COPD is feasible, despite significant palliative supports however, managing terminal symptoms may exceed caregivers' capacity to cope and forced hospital admission (Horton, et al, 2013). However, a carefully planned, individualised, supportive, home-based chronic disease management programs can yield significant cost savings and decrease burdens for some living with advanced COPD.

INSPIRED on line resources

INSPIRED Approaches to COPD (5-part online workshop) - http://www.cfhi-fcass.ca/Elearning/online-workshops/INSPIRED (available at a cost)

The INSPIRED Model of Care for Patients with Advanced COPD (1-hr On Call webinar) – http://www.cfhi- cass.ca/Elearning/OnCall/INSPIRED.aspx (free)

Evaluation: (Young J, et al, 2012)
CANADIAN FOUNDATION FOR HEALTHCARE IMPROVEMENT
http://www.cfhi-fcass.ca/Elearning/spreading-healthcare-innovations-initiative/inspired-approaches-to-copd

Dr Graeme Rocker - who created the INSPIRED[27] program in Halifax, Nova Scotia - has offered to talk about INSPIRED in Manchester when he next visits the UK

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[27] The Canadian Foundation for Healthcare Improvement (CFHI), in collaboration with Boehringer Ingelheim (Canada) Inc. (BICL), is supporting the spread of INSPIRED through its Spreading Healthcare Innovations Initiative.

7. Good practice

7.1 Improving identification of EoL care needs and Advance Care Planning (ACP) to support preferred place of care for patients with COPD.

Solihull Community NHS Care Trust

The Gold Standards Framework in EoL care has been adopted by Solihull Community NHS Care Trust. Patients identified for the Gold Standards Framework (GSF) palliative register access community services through a supportive care pathway which supports holistic assessment, Advance Care Planning and proactive care planning. The pathway has improved the provision of proactive coordinated care for patients with EoL Care needs in the community. However, it was noted that the number of COPD patients accessing the pathway was limited.

7.1.1 Aims and objectives

- To improve identification of patients with end stage COPD in primary care
- To enable proactive coordinated care and support preferred
- Place of care at the EoL

ACP materials were designed by local services (MY COPD and MY LIFE booklets).

The main objectives for the project were to:

- Increase the number of patients with COPD on GSF register from 8% (baseline) to 14% (the national average)
- Increase the number of patients supported in the community on the supportive care pathway
- Monitor the number of patients with COPD on the GP practice GSF who are offered ACP discussions and who have preferred priorities of care recorded
- Monitor achievement of preferred place of death and place of death for patients with COPD

7.1.2 Process

- Baseline data showed that approximately 9% of the total number of patients currently on the GSF registers had an unconfirmed or confirmed diagnosis of COPD
- Staff undertook care of the dying and communications skills training
- The information provided within the training sessions was formalised into local prognostic indicator guidance which along with the 'My LIFE' booklet was shared amongst GPs, community matrons and community respiratory teams
- Patients eligible for the GSF but not currently on the register were identified
- Two GP champions for COPD and EoL were funded for half a day per week
- The team also developed a carer survey which was completed on bereavement

7.1.3 Issues and challenges

Key learning

- Anecdotal evidence from practice staff suggested that the GSF indicators were not as effective as the "surprise" question as a predictor of death at 6 to 12 months. This claim is being explored further
- ACP support benefitted from a locally designed and readily available 'My LIFE' booklet incorporating all the relevant information for COPD patients
- The project team provided training to GPs and community teams
- The integration of the community services and the acute trust resulted in improved communication between the respiratory
- Community team and the EoL provision on the wards
- Overall relationships have also improved between all stakeholders and especially hospices, who now have greater awareness of terminally ill patients with respiratory disease

7.1.4 Findings

- 20/214 patients on the EoL practice registers had confirmed and unconfirmed diagnosis of COPD
- There were 28/247 COPD patients on the register mid post (an increase to 11% of patients)
- At the end of the study, there were 19/266 patients registered on the EoL register with a primary diagnosis of COPD
- For the entire study practices the number of patients dying of COPD at home rose from 20% in September 2010 to 23% in October 2011. The patient satisfaction survey revealed that of those questioned 90% were very satisfied with the overall experience of care they had received to date

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This whole project has led to the consideration of an End of Life Pathway for COPD patients mapped against the End of Life Strategy Framework (see below).

For more information please contact:
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8. Pulmonary rehabilitation

Pulmonary rehabilitation (PR) has developed from being traditionally exercise and education based, to incorporating psychological intervention approaches, self-management strategies and psychosocial support (Howard, et al, 2010). PR should be a key intervention for people with COPD. It has demonstrable efficacy at an early stage in an exacerbation improving functional capacity and quality of life of patients. NICE guidance recommends PR for all people with COPD who consider themselves functionally disabled by COPD and for all those who have had a recent hospitalisation for an exacerbation and evidence suggests that PR may decrease readmission (McDonald & Khor, 2013).

Multidisciplinary PR programmes, incorporating exercise training and education, have been shown to reduce breathlessness and improve exercise capacity in COPD. Building on evidence and NICE guidance, breathlessness services have been successfully developed and the evidence suggests that such services are successful in the palliation of this disabling symptom (Reilly, 2015). Access to a local support group for patients and carers living with breathlessness can help sustain and build upon the positive effects of the BSS in COPD patients, improving patient’s coping skills and overall well-being. However, patients can be too ill to attend PR programmes.

- NICE Quality Standard recommends that people with COPD meeting appropriate criteria are offered an effective, timely and accessible multidisciplinary pulmonary rehabilitation programme
- The Outcomes Strategy for COPD and Asthma and the subsequent NHS Companion Document to the Strategy recommends: Provide pulmonary rehabilitation for all people with COPD with an MRC score of three or above (Aqua Analytics, 2014)

Described below is on PR programme and an “app” which may help carers support patients in their everyday life tasks relating to COPD. PR is also dealt with in depth in the booklet, “Don’t forget to Breathe” (Ward, et al, 2014). Sections in this booklet are excellent and offer an extended picture of what PR can offer COPD patients at all stages in the disease trajectory.

8.1 THE experience of a multidisciplinary programme of pulmonary rehabilition in primary health care from the next of kin’s perspective

8.1.1 Aims

To describe the experience of a multidisciplinary programme of pulmonary rehabilitation in primary health care from the perspective of the next of kin.

8.1.2 Methods

A descriptive qualitative study was undertaken as one element of a longitudinal study comprising a multidisciplinary programme for patients with COPD where the next of kin were invited to one session. Semi-structured interviews were conducted with 20 next of kin.

Despite the programme, a main theme was that carer life was still overshadowed by illness.

Sub-themes included:

- A sense of deepened understanding
- A sense of personal vulnerability
- The programme offered carers a sense of relief from burden as they learned strategies for their own well-being, felt supported by others in the same situation and gained a sense of security by knowing that the patient was being followed
- However, feelings of anxiety persisted and were related to patients' breathlessness and lack of strength, and to what the future might hold
- Carers reported that the programme made their future plans more realistic and, when the patient applied the knowledge acquired, their everyday lives were facilitated
- Although experiencing positive outcomes two years after the programme, the next of kin expressed a need for more support
- This study showed that next of kin could benefit from their own participation and/or that of the patient in a multidisciplinary programme of pulmonary rehabilitation

Next of kin should be offered primary health care support for the sake of their own health, but also in order to manage their informal caregiver role. The experiences described here could form a basis for further development of interventions for next of kin of patients with COPD.

Brief description of the intervention, which consisted of one hour of theory and one hour of physical activity every week:

Meeting 1 - Disease and medication. Physical activity. Anatomy and physiology	COPD nurse and physician
Meeting 2 - Physical activity. Theory. Muscle strengthening	Physiotherapist
Meeting 3 - Nutrition advice. Breathing. Relaxation techniques	COPD nurse
Meeting 4 - Energy saving techniques. Aerobic fitness	Occupational therapist
Meeting 5 - Anxiety and stress. Home training. Management programme	Social worker

Meeting 6 - Next of kin invited and a summary of the information on all topics was presented	All professionals involved Physiotherapist

The COPD nurse was the group leader and participated in every session and advice on smoking cessation was provided throughout the programme (Zakrisson, et al, 2013).

9. **NHS Simple “Flo” telehealth.**

This resource has been described because it may support carers in their day to day life. Flo is a simple system which uses text messages to support people to manage their own health and wellbeing. A film, recently released, shows how Flo can help people to live with COPD.

9.1 How does Flo work?

HCPs can adjust the settings on Flo for each patient, defining when messages should be sent, what information they are asking for and how the system should respond. Flo then sends regular text messages to patients helping them to monitor their health, sharing any information sent back by the patient with the person managing their care[28].

It enables much more detailed and regular monitoring of a person’s health condition than is possible if a patient just attends regular appointments. Clinicians are also able to view real time information about their patients at any time via a simple web interface.

The system was developed by a team at NHS Stoke on Trent (now Stoke Clinical Commissioning Group) to encourage patients to stick to their treatment plans, particularly for long-term conditions such as diabetes or hypertension. The team worked closely with telecommunications partner Mediaburst Ltd to develop a simple system.

A clinical trial showed the impact using Flo had for patients with hypertension and chronic kidney disease. The trial showed better and faster clinical results in managing people’s blood pressure compared to a group of patients who didn’t use Flo. The patients who used Flo also had high levels of patient satisfaction. The trial concluded that, such simple telehealth is acceptable and effective and has the potential for broader use and is accessible for patients who struggle to regularly attend their GP surgery (Cottrell, et al, 2012).

9.2 Rolling out Flo

Encouraging more areas of the NHS to use the Flo system is now the responsibility of nhssimple, a social enterprise. Nhssimple supports health professionals to use Flo and is helping to build a community of people working in health and social care who can share knowledge and learning about the many different ways Flo can be used.

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[28] *For example, a patient with hypertension could be asked to check their own blood pressure each morning and then to text the results back to Flo. If the results are outside agreed limits, Flo will pass this information on to their clinician, while also suggesting that the patient makes an appointment or speak to someone on the phone.*

nhssimple and NHS Stoke-on-Trent CCG have now rolled Flo out to more than 70 health and social care organisations across the UK. It is being used to support an ever growing list of conditions including, asthma, heart failure and stress incontinence. It’s also being used to make sure patients take their medicines, to aid recovery after surgery, and to support people who want to breastfeed, stop smoking or lose weight.

Flo received funding from The Health Foundation in 2011.
http://www.health.org.uk/flo

Film
http://www.health.org.uk/flo?dm_i=4Y2,3TIM4,HLPDD9,DRGMC,1

PART 2. Health care professional (HCP) training

Although patients with COPD have regular contact with health services, access to specialist services and palliative care is poor. Gardiner highlights the need for increased provision for palliative care in COPD, which needs to be alongside dedicated education and training for health professionals (Gardiner, et al, 2010). The COPD-Home is an integrated care model for patients with severe or very severe COPD developed in Norway.

Within the Essex model for Integrated COPD care (A collaborative scheme involving PCT, hospital, community service, general practice, university and Breathe Easy)[29] a COPD modular course in collaboration with the University of Essex Respiratory Consultants and Respiratory Clinic Nurse Specialists has been devised. The course will be either 60 credits towards either a BSc or MSc. The aim is for all the more senior staff involved in the care of COPD to complete the course. The first course began in January 2010.

10. ACP and EOL conversation training

A comprehensive literature review of studies describing communication interventions for patients with COPD and Heart Failure, receiving end-of-life care was undertaken. Three core themes emerged from the synthesis of the literature which would enhance this:

- using education to enhance professional communication skills,
- using communication to improve patient understanding
- using communication skills to facilitate advance care planning (Barnes, et al, 2012).

Staff confidence around advanced communication skills is very low, the training received by cancer clinicians and those available for staff managing patients with long-term conditions varies considerably (NHS, 2011). The following two programmes, “SAGE and THYME, page 99, and “e-LFH health education England”, page103, offer training for HCPs in ACP and EoL conversations and other topics in the field.

10.1 “SAGE and THYME” workshops for ACP and EoL conversations

University Hospital of South Manchester NHS Foundation Trust (UHSM)

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[29] file://nask.man.ac.uk/home$/Downloads/09e415111731b15a32000000%20(1).pdf

The SAGE & THYME®[30] model is a structured and evidence-based approach for dealing with someone worried or in distress. It is taught in a 'SAGE & THYME foundation level' and higher level workshops (see www.sageandthymetraining.org.uk . It was developed by UHSM and a patient in 2006 in response to NICE guidance [31].

The workshops are delivered in two formats, SAGE & THYME Foundation Level Workshop & SAGE & THYME® for ACP and EoL Conversations Workshops[32]

Workshops have been run across the UK and NI with mainly GPs, nurse specialists and 'other' HCPs attending (all designations not specified). An evaluation of over twenty SAGE & THYME ACP workshops run across 8 locations, from December 2012 to May 2014 was undertaken. 413 participants - 48 % in a variety of health care profession roles (mainly nursing) and 31% being GPs – completed pre and post workshop questionnaires.

In general, workshops showed a significance increase in:

- Participants' confidence to begin an ACP conversation
- Their level of confidence in responding to a patient or relative's concerns during an end of life or advance care planning conversation.
- Their level of perceived competence in conducting an advanced care their competence to do so.
- Being more likely to change their practice and use the S & T model

Table 5 SAGE & THYME workshops format

SAGE & THYME Foundation Level	**SAGE & THYME ACP [33]**

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[30] *Connolly M, Perryman J, McKenna Y, Orford J, Thomson L, Shuttleworth J, Cocksedge S. (2010). SAGE & THYME: A model for training health and social care professionals in patient-focussed support. Patient Education and Counseling; 79: 87-93.*

[31] *NICE 2004: Improving Supportive and Palliative Care for Adults with Cancer.*

[32] *Adapted from, Evaluation of the SAGE &THYME® ACP Workshop 27th August 2014. Report. Written by: Joel Coppeard* *http://media.sageandthymetraining.org.uk/sites/default/files/2014-1020%20SAGE%20and%20THYME%20ACP%20Workshop%20Report.pdf*

[33] *Uses a modified version of the original SAGE & THYME model*

Target audience	All levels of social care staff (clinical and non-clinical) wishing to learn or enhance foundation level communication skills across all settings (including non-clinical areas) and disease groups.	Senior staff who engage in advance care planning/end of life care conversations/know the GSF (e.g. GPs, healthcare staff, social workers, lawyers)
Previous experience required	None	Experience of ACP / EoL care/ GSF
Aims	To provide a structured approach to dealing with concerns To teach foundation level communications skills for talking to people in distress and has the following aims for participants, to; **R**ecognise psychological distress **A**void causing psychological harm **C**ommunicate honestly and compassionately **K**now when they have reached the boundary of their competence.	To provide a structured approach to addressing advance care planning issues and dealing with concerns To provide a structure for initiating conversations and then listening and responding to patients or carers, when discussing ACP or EoL care issues. Participants focus on effective communication skills that help open an ACP conversation. The structure provides a consultation guide as concerns and issues are disclosed
Duration of workshop	3 hours	3.5 hours
Number of learners per workshop	30	30
Workshop format	Lecture, small group work and interactive rehearsals	Lecture, small group work and interactive rehearsals[34] Working at level 2 of the level 4 NICE communication model[1].
Workshops delivered by	UHSM and other organisations with a licence	UHSM

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[34] *N.B. The workshop does not cover: breaking bad news; the Mental Capacity Act; or specific documents such as 'preferred priorities of care'.*

Table 6 SAGE & THYME Advanced Care Planning model

Setting	Find/create a good time and place to talk. Think about triggers/cues and who should or should not be included.
Acknowledge/ ask	"I'm aware that you have just been in hospital again, what thoughts do you have about have about how things may be in the future?"
Gather	Gather all concerns- reflect and summarise what the patient has said. Pick up cues. Screen: "Is there something else on your mind/worrying you?"
Empathy	"You have been through so much over that last few week I'm not surprised you are feeling..."
Talk	"Who supports you?" "Who can you talk to?"
Help	"How do they help?" Each person may provide different support.
You	"What would help right now/today/in the future?" "What do you think would help?" Screen for more ideas they may have: "What else would help?"
Me	"Is there something you would like me to do?" Wait for a response, THEN offer something you think may help if appropriate. Introduce written plan.
End	Summarise and close "We have started to discuss these important issues, we can talk again next time we meet." "Is it OK to leave it there today?"

The workshops meet:

- NICE guideline on Communication level 2
- Statement 13 from the NICE quality standard for COPD
- NICE commissioning guides on services for people with chronic obstructive pulmonary disease [CMG43] Published date: October 2011)
- Guide for commissioners (Department of Health, 2012).

People with COPD and their carers need to know that if they are approaching the end of life their preferences for care will be discussed with them and every effort will be made to meet their needs and their preferences (outcomes strategy doc). Given the evidence that HCPs are reticent to initiate End of Life conversations for various reasons, the S&T model appears to offer a template for them to structure and follow these conversations. Participants also felt more able to respond to the questions and concerns of family carers.

UHSM trains others to become SAGE & THYME facilitators and licences their organisations to deliver SAGE & THYME foundation level workshops.

If the MHMC project team is interested in commissioning a workshop, or in training staff to deliver these please contact:

Joanne Thomas,
SAGE & THYME team:
Email: Joanne.thomas@cmft.nhs.uk
Tel: 0161 276 6965
www.sageandthymetraining.org.uk

See Appendix 1, for an Executive Summary of the S&T evaluation.

http://media.sageandthymetraining.org.uk/sites/default/files/2014-10

10.2 e-LFH health education England programme

EoL Care for All (e-ELCA) is an e-learning programme that aims to enhance the training and education of health and social care staff and volunteers involved in delivering EoL care.

The programme was commissioned by the Department of Health and developed by HEE e-Learning for Healthcare (e-LfH), in partnership with the Association for Palliative Medicine of Great Britain and Ireland, to support the implementation of the Department of Health's 2008 national EoL Care Strategy.

There are over 150 e-learning sessions available across eight themed modules regularly reviewed by experts to ensure they are up to date and reflect current good practice. This programme is a very comprehensive learning of all aspects of EoL care contained in an 8 topic matrix with the learning objectives for each session.

e-ELCA sessions have been mapped to the QCF levels 2, 3 and 5 end of life care units and to the nine high-level learning objectives in the One Chance to Get it Right report developed by the Leadership Alliance for the Care of Dying People in 2014 (page 35)

These comprise:

- Relationship between palliative care and EoL care
- Introduction to principles of ACP
- Introduction to e-ELCA
- Relationship between palliative care and EoLcare
- ACP sessions (principles, context, process, developing practice)
- Assessment module (principles, domains, context & process)
- Communication skills – (principles, basic skills, modes of communication, specific contexts, challenging scenarios)
- Symptom management – principles, pain, breathlessness, nausea, vomiting, constipation, emergencies, last days of life, mood, advanced illness)
- Integrated learning (Initiating conversations about EoL care, condition specific case studies, critical situations, scenarios around dying, care after death, frameworks and tools,
- Social care sessions
- Bereavement sessions

For details of learning objectives http://www.e-lfh.org.uk/media/191504/Revised-ELCA-topic-matrix-June-15.pdf

There are different HCP learning pathways:

- Primary care
- Social care
- Secondary care - using e-ELCA on e-LfH Hub
- Secondary care - using e-ELCA on National Learning Management System (ESR)
- Priorities for Care of the Dying Person - doctors - nurses - allied health professionals - social care - managers - social care workers - healthcare managers - healthcare administrators

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35 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf). All sessions can be found on the Skills for Care website. http://www.skillsforcare.org.uk/Skills/End-of-life-care/End-of-life-care.aspx

Proposed pathways:

- Ambulance crew
- Medical students
- Volunteers
- GP trainees
- Administration and management staff
- Nurses in the acute sector
- Induction of band 5 nurses to specialist palliative care services – Oxford
- Palliative care in acute medicine - Core Medical Training doctors
- Foundation training – doctors

A small number of selected sessions are freely available to volunteers, clerical and administrative staff on an open access website.These are:

- Introduction to e-learning for EoL care
- Relationship between palliative care and EoLccare
- Introduction to principles of ACP
- Introduction to principles of assessment in EoL care
- Part 1: Introduction to principles of assessment in EoL care
- Part 2: The importance of good communication
- Principles of communication
- Communicating with ill people
- Talking with ill people: considering the surrounding environment
- Culture and language in communication
- Communication skills for admin staff, volunteers and other non-clinical workers
- General approach to assessment of symptoms
- Agreeing a plan of management and care
- Communicating the plan of management and care

www.endoflifecareforall.com

http://www.e-lfh.org.uk/programmes/end-of-life-care/

Communication and training in EoL care for staff is key, additional EoL care e-learning modules for health and social care professionals are available free from the National End of Life Care Programme website:

www.endoflifecareforadults.nhs.uk/education-and-training/eelca

10.3 Advanced decisions

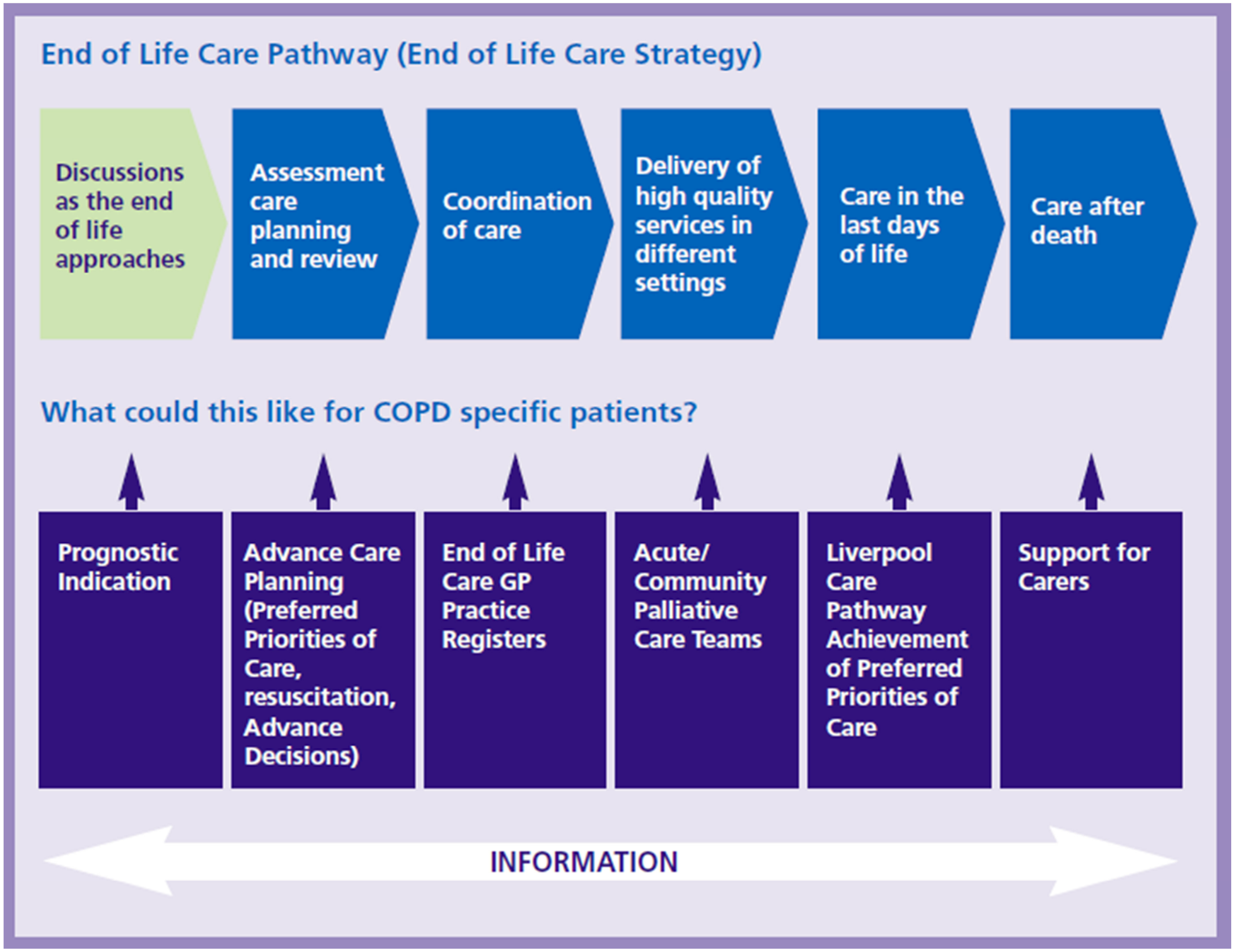
ADAssistance, a charity which provides CPD training to professional groups in Advanced Decision making

www.ADassistance.org.uk

10.4 COPD EoL management pathways

The NHS Improvement - Lung National Improvement Projects (2011) discussed above has considered an EoL pathway for COPD patients. The three projects within the EoL care work stream have focused on testing key elements of the EoL care pathway which features in the Department of Health End of Life Strategy (2008). This contains all the components of a gold standard approach to care and is the model against which NHS organisations should aim to plan their services. The diagram below illustrates an adaptation of this to meet the needs of COPD patients.

Figure 2 End of Life Care Pathway and COPD



11. COPD Specific management guidelines

The following section provides an introduction to current guidelines for health professionals working in COPD.

11.1 “GOLD”

Global Strategy for Diagnosis, Management, and Prevention of COPD

The GOLD report, Global Strategy for the diagnosis, management, and prevention of COPD, is based on the most highly validated current concept of COPD pathogenesis and the available evidence on the most appropriate management and prevention strategies. It concludes that there is considerable evidence to show that management of COPD is generally not carried out in accordance with current guidelines. According to the GOLD report, an effective COPD management plan should include assessing and monitoring the disease, reducing risk factors, managing stable COPD and managing exacerbations. The guidelines suggest that integrated care interventions that include education, coordinate levels of care and improved accessibility have shown positive effects on QOL and hospital admissions (Sunde, et al, 2014).

In 2011, GOLD released a consensus report, Global Strategy for the Diagnosis, Management, and Prevention of COPD. It recommended a major revision in the management strategy for COPD IN 2001. Updated reports released in January 2013, January 2014, and January 2015 are based on scientific literature published since the completion of the 2011 document but maintain the same treatment paradigm. Assessment of COPD is based on the patient’s level of symptoms, future risk of exacerbations, the severity of the spirometric abnormality, and the identification of comorbidities.

The GOLD report is presented as a “strategy document” for health care professionals to use as a tool, to implement effective management programs based on available health care systems. The quadrant management strategy tool is designed to be used in any clinical setting; it draws together a measure of the impact of the patient’s symptoms and an assessment of the patient’s risk of having a serious adverse health event in the future. Many studies have assessed the utility/relevance of this new tool. Evidence will continue to be evaluated by the GOLD committees and management strategy recommendations modified as required.

The GOLD initiative will continue to work with National Leaders and other interested HCPs to bring COPD to the attention of governments, public health officials, health care workers, and the general public to raise awareness of the burden of COPD and to develop programs for early detection, prevention and approaches to management.

Although there are sections on: hospital discharge and follow-up, home management of exacerbations and prevention of COPD exacerbations, EoL specifically is not included.

http://www.goldcopd.org/

11.2 NICE (2010) COPD: Management of COPD in adults in primary and secondary care (partial update)

This guidance updates and replaces NICE clinical guideline12 (published in February 2004). It is written for people with COPD but it may also be useful for their families or carers or for anyone with an interest in the condition. The advice in the NICE guideline covers the diagnosis, treatment and care of adults with COPD. However, End of Life is not covered in these guidelines although pulmonary rehabilitation is addressed. It is based on Evidence Update 5.[36]

11.3 Department of Health (2011) An outcomes strategy for (COPD) and asthma in England

Supports the Carers Strategy and its four priority areas for improved support, which apply to people caring for people with COPD as much as for any other condition:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well.

11.3.1 Community pharmacy services

Community pharmacy services will support people with COPD and asthma such as stop smoking services and medicines use reviews. These will be available to people close to home and at times convenient to them. The introduction of national target patient groups for medicines use

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[36] *Chronic obstructive pulmonary disease: Evidence Update February 2012. A summary of selected new evidence relevant to NICE clinical guideline 101 'Management of chronic obstructive pulmonary disease in adults in primary and secondary care' (2010)*

reviews (MURs) to ensure they are provided to those who will benefit the most. One of the national target groups will be patients with respiratory disease. New services, delivered through community pharmacies, are expected to be introduced from October 2011 including:

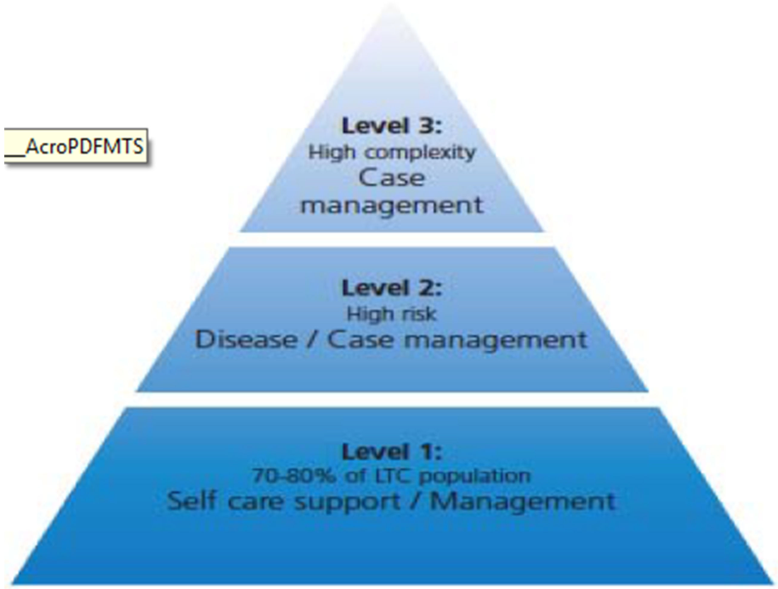
The introduction of a New Medicine Service (NMS) to help improve medicines adherence for people with long-term conditions newly prescribed a medicine (Patients with COPD will be one of the areas the service will initially focus on)

Both of these services should benefit patients with COPD in supporting them to take their medicines as intended and helping to improve their lifestyles, in particular stopping smoking.

11.3.2 COPD care as a long term complex condition

The Triangle below depicts how any Long Term condition will be managed.

__AcroPDFMTS

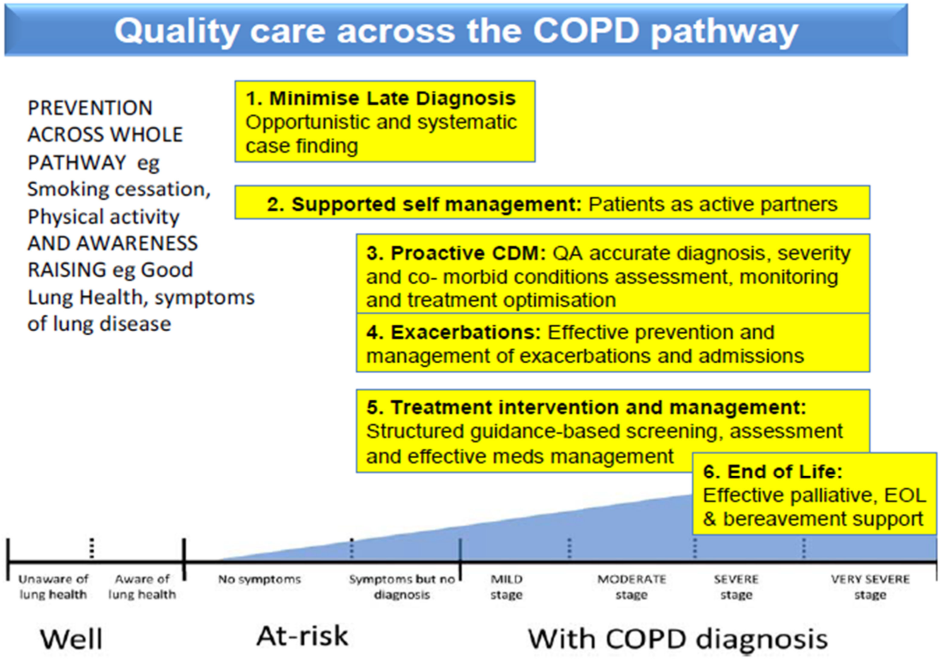


Level 1: depicts **Risk profiling**

Level 2: how **Integrated Care Teams** can provide joined up and personalised services, putting in specialist services when necessary and treating a person holistically, regardless of their condition(s)

Level 3: **Self Care,** whereby there should be a systematic transfer of knowledge and power to people with long-term conditions, to empower them to maximise self-management and choice. This includes ensuring that; people engage in shared decision making in order to co-produce a care plan, that both they and their carers have access to the appropriate information about how to manage their condition; and that there is ‘no decision about me without me’ being active participants in all decisions about their care. The importance and value of self-care and education should be fully understood and shared decision-making and supported self-care are seen as integral elements of LTC management.

The fourth element in this process is the need to implement all of the three elements.



Quality care across the COPD pathway

PREVENTION ACROSS WHOLE PATHWAY eg Smoking cessation, Physical activity AND AWARENESS RAISING eg Good Lung Health, symptoms of lung disease

1. Minimise Late Diagnosis Opportunistic and systematic case finding

2. Supported self management: Patients as active partners

3. Proactive CDM: QA accurate diagnosis, severity and co- morbid conditions assessment, monitoring and treatment optimisation

4. Exacerbations: Effective prevention and management of exacerbations and admissions

5. Treatment intervention and management: Structured guidance-based screening, assessment and effective meds management

6. End of Life: Effective palliative, EOL & bereavement support

(Department of Health, 2012, pp. 37-38)

Specifically in relation to COPD and models of care, the evidence shows that delivery of services for people with COPD are effective where an integrated care model is developed using multidisciplinary teams. The diagram below shows what quality care across the COPD trajectory should look like. The triangle represents the COPD patient population in primary care. The strategy is based on the Wagner Chronic Care Model (Wagner et al, 1996) which emphasizes the interactions between primary and secondary care, and between patients who take an active role in their care and their health care providers.

11.4 Services for people with chronic obstructive pulmonary disease: CMG43 Guide for commissioners

NICE commissioning guides [CMG43] Published date: October 2011 advocates:

- Early recognition and assessment
- Advance care planning
- Continued intervention
- Coordination of care and access to a full range of services
- Care in the last days of life
- Care and support after death
- Service models

Commissioning supportive and palliative care for people with COPD, underpinned by NICE guidance, the NICE quality standard for COPD (see page 109) and NICE quality standard for EoL Care, will contribute to achieving outcomes under domain 4 of the NHS Outcomes framework 2011/12.

Commissioners should consider the **skills and competencies** needed by health and social care staff to identify and address the supportive and palliative care needs of people with advanced COPD, for example:

- communication skills
- assessment and care planning
- advance care planning
- symptom management.

The guide also offers advice on:

- Advance care planning
- Continued intervention
- Coordination of care and access to a full range of services
- Care in the last days of life
- Care and support after death

https://www.nice.org.uk/guidance/cmg43/chapter/43-specifying-supportive-and-palliative-care-for-people-with-copd

11.5 NHS (2012) COPD Commissioning Toolkit: a resource for commissioners (Gateway reference 17874)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212876/chronic-obstructive-pulmonary-disease-COPD-commissioning-toolkit.pdf

11.6 Breathlessness IMPRESS Tips (BITs) for commissioners

These provide some guidance to commissioners about how to support and incentivise the local healthcare system to take a symptom-based rather than a disease-based approach to assessment and care of adults who have long-term breathlessness. Taking a symptom-based approach has advantages because it:

- Can harmonise potentially different approaches advised by different specialties to assessment and treatment of breathlessness and therefore reduce variation
- Guides the system to start at the point where people present to primary care - with symptoms not diagnoses - and suggests how to support the system to increase diagnosis rates in at least three under-diagnosed conditions including COPD,[37] which, if left untreated cause significant morbidity and high use of acute services
- Has the potential to address multi-morbidity. For example, only 14-18% of people with COPD only have COPD and when actively assessed for co-morbidities it may be as low as 3%. If not all of the morbidities are diagnosed and managed, this will also worsen health outcomes and may lead to higher use of unscheduled care
- Can also address the complex interaction between mental and physical health

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[37] *The other two being, heart failure and anxiety.*

- Requires the healthcare system to be alert to patients' capabilities, opportunities and motivation for healthy or unhealthy behaviours that contribute to their symptom, and to one or more underlying condition and to "make every contact count."

Whilst there are clinical guidelines for a number of aspects of breathlessness assessment and care, these tend to be disease-specific, for an individual and often do not have cost-effectiveness data. Therefore there remains much uncertainty about how to commission for a population that takes account of multi-morbidity, outcomes and cost. These BITs for commissioners aim to fill in some of those gaps. They are not meant to ignore the local context and the services currently provided, but rather they should be adapted and interpreted on the basis of what local services are already in place.

file://nask.man.ac.uk/home$/Downloads/Breathlessness%20IMPRESS%20Tips%20for%20commissioners%20FINAL%202014-02-25%20with%20activated%20hyperlinks%20(2).pdf

Also, the importance of QIPP with funding models for Long term care support and local implementation is discussed

http://www.impressresp.com/index.php?option=com_content&view=article&id=5&Itemid=4

For Key NHS policy documents which can aid health service providers in understanding commissioning responsibilities and aspirations. There are pages on:

- National strategies
- Operating Framework for the NHS in England
- Policy Analysis

http://www.impressresp.com/index.php?option=com_content&view=article&id=5&Itemid=4#sthash.tKMTiSXg.dpuf

11.7 Consultation on a Strategy for Services for COPD in England

A current consultation document advocates that People with COPD should have access to specific supportive care, including where necessary:

- a comprehensive holistic needs assessment leading to a care plan

- active management of dyspnoea
- active management of pain
- identification and management of anxiety and depression
- management of cachexia and fatigue
- management of nausea and vomiting
- assessment and provision of home oxygen for palliation of symptoms
- assessment of information needs
- choice about place of care in management of acute exacerbations
- preference for non-invasive or invasive ventilation and DNAR (‘Do not attempt resuscitation’)
- religious and spiritual support
- recognition of the dying phase, with planned and co-ordinated care
- preferred place of end-of-life care and death discussed with patient and relatives
- social and financial support
- advance care planning, for example using Preferred Priorities for Care
- access to equipment
- support for carers, including into bereavement (Department of Health, 2012**)**

Recommendations include that there should be improved access to high quality EoL services that ensure equity in care provision for people with severe COPD, regardless of setting and access to information and appropriate support should be available for carers and those who are bereaved.

To support implementation, the Department of Health will take the following actions (subject to available funding).

- ○ Action 30: Pilot markers of a prognostic indicator to identify the end-of-life care phase for people with COPD.
- ○ Action 31: Publish core workforce skill requirements for end-of-life care in people with COPD.
- ○ Action 32: Pilot and evaluate an end-of-life care pathway for people with COPD, and also evaluate different models of support for carers.

This leaves local health and social care communities and the third sector taking responsibility for this service. This strategy reviews the case for change and describes the good practice that is already taking place in the NHS to deliver good COPD services. National targets or milestones have not been set yet but these will be made clear at a later date. For this reason the strategy also describes how (subject to available funding) the Department of Health will take action to support the improvement of services for people with COPD. Full implementation of the strategy will mean that all people with COPD and those who care for them would have the best possible healthcare and support.

The natural history of COPD means that there are people who, as their disease advances (particularly as the EoL approaches), require palliative care as well as continuing disease management. This need can be difficult to identify unless the impact of the disease on the individual’s daily life is assessed (NHS, 2011).

11.8 Improving care for COPD: Implementing NICE Quality Standard 10, Statement 13

Statement 13 from the NICE quality standard for COPD advocates that people with advanced COPD, and their carers, are identified and offered palliative care that addresses physical, social and emotional needs.

To enable early recognition and assessment of the supportive and palliative care needs of people with COPD, commissioners should:

- Work with clinicians to agree the indicators or triggers for advanced COPD, which can be used to identify when a person's supportive and palliative care needs should be assessed (see definitions under statement 13 of the NICE quality standard for COPD for examples)
- Ensure EoL care is an integral component of the care plan of people with advanced COPD
- Be satisfied that primary care teams ensure that the palliative care needs of people with advanced COPD are regularly assessed, and that information is communicated within the primary care team. This includes out-of-hours services and other health and social care staff
- Be satisfied that a key worker is identified for people with advanced COPD and that the person, their family and carers know who their key worker is and how to contact them
- Ensure that information regarding long term oxygen therapy non-invasive ventilation and EoL care is made available for people with COPD, their families and carers while they are in a stable state. This is so that decisions regarding future care can be made in advance

Commissioners should consider the **skills and competencies** needed by health and social care staff to identify and address the supportive and palliative care needs of people with advanced COPD, for example:

- communication skills
- assessment and care planning
- advance care planning

- symptom management

A literature review has been undertaken to identify, reference and summarise the current evidence base regarding effective interventions relating to the NICE QS above (Brown, 2014).

12. Examples of good practice in the UK

12.1 “Bringing healthcare home”

This programme at Airedale NHS Foundation Trust set out to make EoL care simpler for people in their last year of life (and their carers), to support people to die in the place of their choosing. There were three parts to the project:

- developing an electronic system to help health professionals to co-ordinate EoL care
- training staff to start conversations around death and dying with people in their care; and
- the Gold Line

This was with a view looking at local quality of care and patient experience for people in their last year of life, identifying where there were gaps and where things were working well. In a separate initiative, Airedale Hospital are developing a project to use video consultations between patients and health professionals (i.e. telemedicine) to support care outside hospital and particularly in care homes.

12.2 IMPRESS: How to improve quality and productivity by integrating COPD care - North Tyneside example

The IMPRESS[38] synthesis of current evidence and policy is also illustrated by a report about North Tyneside’s integrated care pilot focusing on COPD.

The requirement to find efficiency savings of 4-5 per cent a year requires fundamental changes in the way hospitals are used

A transformation of systems to provide value for people with long term conditions is seen as critical to success. The potential for better coordination and for integrating care across a pathway linking home, primary and community services, hospital and social care is considered by policy makers to be significant. The hypothesis for integration is that if there is a clear vision to make a difference to service users, and to

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[38] IMPRESS was set up in 2007 as a joint initiative between the British Thoracic Society (BTS) and the Primary Care Respiratory Society-UK (PCRS-UK) to provide clinical leadership to the NHS to stimulate improvement and integration in respiratory services. Core IMPRESS costs have been met by restricted educational grants from the Department of Health England, and unrestricted educational grants from AstraZeneca, Boehringer Ingelheim Ltd/Pfizer Ltd and GlaxoSmithKline (GSK) since the establishment of the initiative in 2006. The IMPRESS team has representation from primary and secondary care, nursing and medicine, public health, social care, providing and commissioning and lay views. They have worked through numerous issues that local teams need to address to improve care across the system and provide practical and highly-regarded guidance through our website. www.impressresp.com

monitor progress, if health and social care resources are concentrated on the people who most need them, at the right time, there will be better outcomes and less wasteful use of resources

This report is on one of the national integrated care pilot sites, including patients with COPD. It suggests a bundle of activities that are needed:

- care planning
- allocation of a key/named worker
- routine measurement and feedback to primary care,
- robust patient assessment and referral to key services such as pulmonary rehabilitation
- education and support for patients and professionals
- recording and provision of consistent information across primary and secondary care

The report also illustrates how investment in relationships over time is greatly advantageous and how much can be achieved outside the commissioning system, by providers alone. In Northumbria the staff group who have made the biggest changes have been the community nursing staff and for whom detailed proactive management of individuals with long term conditions was not in their traditional job description. What is happening illustrates the potential impact of integrated care on patient experience, quality of diagnosis, care and admissions and how, when supported appropriately by hospital specialists and social care specialists and working in a culture of trust, general practice can drive system change for the benefit of patients.

It explains the potential for social care services such as support for carers and community alarm services as well as home support to be better integrated into care pathways to support patients and makes the case for a consistent care approach to other long term conditions, particularly heart disease and diabetes, and for regular medication reviews.

It demonstrates four sorts of integration:

- Centring on an individual irrespective of long term condition
- Between primary and secondary care decision-making
- Between general practice and community nursing
- Between health and social care

12.2.1 Next steps

They plan to protect and sustain models of flexible working, such as practice nurses doing home visits in areas where they have particular expertise, district nurses undertaking more chronic disease management. This would ideally include:

- Creation of a more appropriate tariff that reflects the revised workloads of the parties in the system: for example, the proactive care and care of acutely ill patients managed by primary and community nursing for a range of chronic diseases. This requires commissioner input and will form part of the quality, improvement, productivity and prevention (QIPP) response.
- Plan for vertical integration between the care trust and acute trust that would offer negotiated packages of flexible support for practices/practice clusters
- Explore the potential of personal budgets and re-ablement
- Continue care planning training and implementation adapted from Year of Care training

What next for social care re-ablement

- There is a successful facilitated discharge team for stroke and the model could be repeated for COPD, if the team can meet patients' needs and help them overcome fear
- 150 staff have been through re-ablement and daily living skills training, and some have also received training from the lead physiotherapist on pulmonary rehabilitation: more sessions are planned, social care is working with its training section to develop training opportunities/programmes for frontline staff in the council and the independent sector; core competencies are to be agreed with therapists to ensure that the training is tailored to support the needs of patients in the community

12.2.2 The role of the home support team in EoL care

Whilst this is not something that is specifically done for patients with any particular long term condition because the focus is on re-ablement, there is nothing in the model to stop support workers enabling a person to die at home. The social care lead has been working with the Marie Curie team and a number of staff have accessed the training as part of an EoL work stream. The service is responsible for training independent providers, and so there is a roll-out planned of all of the re-ablement training.

With the right funding attached the knowledge and skills needed to support people with COPD could be included (British Thoracic Society, 2011).

12.3 Improving identification of EoL care needs and ACP to support preferred place of care for patients with COPD - Solihull Community NHS Care Trust

The GSF in EoL care has been adopted by Solihull Community NHS Care Trust. Patients identified for the (GSF palliative register access community services through a supportive care pathway which supports holistic assessment, ACP and proactive care planning. The pathway has improved the provision of proactive coordinated care for patients with EoL care needs in the community. However, it was noted that the number of COPD patients accessing the pathway was limited.

12.3.1 Aims and objectives

- To improve identification of patients with end stage COPD in primary care
- To enable proactive coordinated care and support preferred
- Place of care at the EoL

ACP materials were designed by local services (MY COPD and MY LIFE booklets).

12.3.2 Objectives

The main objectives for the project were to:

- Increase the number of patients with COPD on GSF register from 8% (baseline) to 14% (the national average)
- Increase the number of patients supported in the community on the supportive care pathway
- Monitor the number of patients with COPD on the GP practice GSF who are offered Advance Care Planning discussions and who have Preferred Priorities of Care recorded
- Monitor achievement of preferred place of death and place of death for patients with COPD.

12.3.3 Process

- Baseline data showed that approximately 9% of the total number of patients currently on the GSF registers had an unconfirmed or confirmed diagnosis of COPD.
- Staff undertook care of the dying and communications skills training
- The information provided within the training sessions was formalised into local prognostic indicator guidance which along with the ‘My LIFE’ booklet was shared amongst GPs, community matrons and community respiratory teams.
- Patients eligible for the GSF but not currently on the register were identified
- Two GP champions for COPD and End of Life were funded for half a day per week
- The team also developed a carer survey which was completed on bereavement.

12.3.4 Issues and challenges

Key learning

- Anecdotal evidence from practice staff suggested that the GSF indicators were not as effective as the “surprise” question as a predictor of death at 6 to 12 months. This claim is being explored further.
- Advance Care Planning support benefitted from a locally designed and readily available ‘My LIFE’ booklet incorporating all the relevant information for COPD patients.
- The project team provided training to GPs and community teams.
- The integration of the community services and the acute trust resulted in improved communication between the respiratory
- Community team and the end of life provision on the wards.
- Overall relationships have also improved between all stakeholders and especially hospices, who now have greater awareness of terminally ill patients with respiratory disease.

12.3.5 Findings

- 20/214 patients on the End of Life Practice registers had confirmed and unconfirmed diagnosis of COPD.
- There were 28/247 COPD patients on the register mid post (an increase to 11% of patients).
- At the end of the study, there were 19/266 patients registered on the EoL register with a primary diagnosis of COPD.
- For the entire study practices the number of patients dying of COPD at home rose from 20% in September 2010 to 23% in October 2011. The patient satisfaction survey revealed that of those questioned 90% were very satisfied with the overall experience of care they had received to date.

Contact:

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Solihull NHS Care Trust
Tel: 0121 329 0179
Email: sandy.walmsley@solihull-ct.nhs.uk

This whole project has led to the consideration of an End of Life Pathway for COPD patients mapped against the End of Life Strategy Framework (see below).

For more information please contact:

Hannah Wall, National Improvement, Lead for EoL Care and Asthma

hannah.wall@improvement.nhs.uk

13. UK: Community based respiratory services

13.1 Dorset’s future desired state document for COPD; bronchiectasis; pulmonary fibrosis.

Dorset Clinical Commissioning Group, and the Pan Dorset Respiratory Strategy Group. Developing a new model of care for patients with COPD, Bronchietasis and Pulmonary Fibrosis (2012).

This document provides a review of evidence for recommended clinical interventions by Dorset’s respiratory strategy group, and a description of national respiratory models tailored to managing people in their own homes.

The review of existing/on-going community-based respiratory services across the UK includes:

13.1.1 North Tyneside COPD Integrated Team includes palliative care

(see above, page 118)

13.1.2 South East Essex integrated COPD service

Includes a COPD training course, whereby all staff could collect points towards a degree. It’s a 12- week education course with 13 sessions. The course covers all aspects of COPD care including practical exams. All community matrons are trained up to this level.

13.1.3 Colchester integrated COPD service team

Working towards developing a patient education forum which will allow an education of patients at a much earlier stage of their condition. Working towards improving ED profile to enable better support for patients discharged from ED. Developing educational support from HCP’s working with COPD

13.1.4 Salford integrated COPD service

Development of an integrated COPD pulmonary disease service model aimed at improving the management of COPD by better integration of healthcare services, streamlining patient care pathways, and facilitating access to services close to patients' homes.[39]

A health needs analysis and benchmarking exercise was undertaken. These activities were then used to develop an integrated service model in order to improve the diagnosis and management of COPD and reduce unscheduled hospital admissions and length of stay.

Following implementation of the model, these are the initial findings and 12-month results:

- A further 811 patients were diagnosed.
- Unscheduled hospital admissions for COPD fell from 935 to 840
- Length of stay was reduced from 8.3 to 7.7 days
- Associated costs fell from £1,772, 865 to £1,528,080.
- The number of patients who completed pulmonary rehabilitation increased from 84 to 143.

Conclusions:

An integrated COPD service model was successful in increasing diagnosis, reducing hospital admissions and reducing length of hospital stay – in line with the proposed National Strategy for COPD Services in England.

It also promoted management according to National Institute of Health and Care Excellence (NICE) guidelines.

On-going: Patient education

- End of life care work is on- going
- Working on the redesigning of pulmonary rehabilitation
- Beginnings of an Oxygen safety project. (Roberts, et al, 2010).

Contact:

Mrs June Allison Roberts,
Department of Respiratory Medicine,

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[39] Involving Foundation Trust, Salford, Greater Manchester, UK Department of Respiratory Medicine, Salford Royal NHS

GSK, Uxbridge, UK

Salford Royal NHS Foundation Trust,
Room 336 ClinicalSciences Building,
Tel: +44 (0)161 206 3156 Fax: +44 (0)161 206 4189
E-mail: june.roberts@nhs.net

13.1.5 Southampton's COPD integrated team

An integrated care pathway in COPD involving palliative care medicine at Aintree University Hospitals NHS Trust (NHS Improvement, 2011) to trial an inter-disciplinary model integrating respiratory and palliative medicine specialties focusing on end of life care in COPD patients.

For a copy of Dorset's Future Desired State Document for COPD; Bronchiectasis; Pulmonary Fibrosis contact:

Sara Moseley
Community Solutions Programme Manager,
Wessex HIEC.
Faculty of Health Sciences,
University of Southampton,
SO17 1BJ

14. International: community based respiratory services

14.1 Norway, "COPD–Home" - The role of the home care nurse

In Norway, local authorities provide free home-care nursing programmes. Both authorised nurses and home-care nurses are employed to visit people in their own home. Home-care nurses administer medication, provide meals or assist in bathing for many persons with severe COPD. The authors hypothesise that when equipped with adequate knowledge, tools and communication for backup support to effectively respond to patients' needs, home-care nurses can play an important role in home monitoring of symptoms associated with COPD exacerbations. Their work may result in reducing the number of COPD exacerbations per year, reduction in the overall use of healthcare services, increased QOL, less anxiety and depression, and improved coping.

A single centre, prospective, open, controlled clinical study comparing COPD-Home integrated care (IC) with usual care (UC). The aim of the "COPD–Home" model is to develop, implement and evaluate it as an integrated[40] means of bringing patients' and primary healthcare workers' competences and behaviours more in line with guidelines for pharmacological and non-pharmacological interventions.

A principle of the COPD–Home model is that hospital treatment should lead to follow up in the patient's home. The model also includes education, improved coordination of levels of care, improved accessibility and a management plan. The home-care nurse has a major role in the COPD–Home model, its ultimate aim being to evaluate its ability to assist both healthcare workers and planners to improve the management of COPD, reduce exacerbations and improve QOL and coping among patients with COPD. Sunde, et al (2014) worked with patients with severe and very severe COPD (Gold III–IV) [41] that had been hospitalised due to a COPD exacerbation

14.1.2 COPD-Home comprises:

Increased degree of integrated care

- education provided by an education programme for patients and nurses
    - 15-min interactive COPD education for patients
    - systematic education of home-care nurses

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[40] *The World Health Organization defines the concept of 'integrated care' as bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration being the means by which services can be improved in terms of access, quality, user satisfaction and efficiency (Grone O, Garcia-Barbero M. Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. Int J Integr Care 2001; 1: 21.)*

[41] *The Global Initiative for Chronic Obstructive Lung Disease (GOLD) criterion for COPD classifies the disease in stages I–IV (mild, moderate, severe and very severe) according to the value of FEV1 as per cent of predicted value.*

  - joint visits in the patient's home
  - call centre for support and communication with the GP and home –care nurse/patient
  - individual self-management plans for pharmacological and non-pharmacological intervention to manage stable COPD and exacerbations
  - tools to monitor disease
  - medication easily available in the patient's home to manage exacerbations (Sunde, et al, 2014).

Participants were required to have scheduled a minimum of one visit per week.

- Findings of the study two years later were that during the year prior to study start there were 71 hospital admissions (HA) in the intervention group with a reduction in HA during the first year of follow-up and a 46.5% reduction during the second year.
- During the year prior to study start, the number of hospital days (HD) was 468 and this was reduced by 48.3% during the first year and remained low during the second year of follow-up.
- The number of HD remained unchanged during the follow-up period.
- Intervention according to the COPD-Home model reduced hospital utilization in patients with COPD III and IV with a persisting effect throughout the 2 years of follow-up.
- However, there was a trend towards a shorter survival time (Titova, et al, 2015).

Although the resources are in the Norwegian language, these can be accessed by arrangement.

(These comprise: Interactive e-learning COPD and 9 different instructions in inhalations preparations & Motivation courses quit smoking).

Please contact Synnove.Sunde@stolav.no

PART 3. General EoL care

Part 3 offers evidence and resources and information from previous EBS scans for the support and education of people caring for people at the end of their lives. This information pertains to all conditions and contains details of one to one and group education courses, and includes audio and visual material. There is also a section of clarification of terminology for carers and two examples of nursing skills acquisition for carers.

15. Good practice

15.1 The GOLD Line

The Gold Line is a 24/7 telephone service for people considered to be in their last year of life, and their families across Airedale, Wharfedale, Craven and Bradford. Senior nurses at Airedale Hospital are available to answer calls, provide direct advice and support, can contact other services and arrange admissions and home visits as required. As well as telephone support, there are some iPads available, which allow nurses to see people face to face via a secure video link.

Nurses answering calls to the Gold Line have access to patients' health care records, and can offer practical support – such as around managing pain medication – as well as emotional support. The Gold Line now works with nearly 1,200 people in their last year of life, and the nurses answer more than 500 calls from people each month. The care provided by the nurses running the helpline and the services they coordinate, has meant that a significantly higher proportion of people have been able to die in the place of their choosing (usually at home) than the national average.

15.2 Bringing health care home

The **'Bringing Healthcare Home'** programme at Airedale NHS Foundation Trust set out to make EoL care simpler for people in their last year of life and their carers, and to support people to die in the place of their choosing. There were three parts to the project: developing an electronic system to help health professionals to co-ordinate End of Life Care; training staff to start conversations around death and dying with people in their care; and the Gold Line. This was with a view looking at local quality of care and patient experience for people in their last year of life, identifying where there were gaps and where things were working well. In a separate initiative, Airedale Hospital was developing a project to use video consultations between patients and health professionals (known as telemedicine) to support care outside hospital and particularly in care homes. The Gold Line brought together these two areas of work. The business development team at Airedale Hospital saw an opportunity to apply for funding to add an EoL service to its telemedicine hub.

A team from Airedale looked at how effective the Gold Line is and found that, as a result of calls to the Gold Line, significant numbers of people avoid attending accident and emergency, having to be admitted to hospital, and calling out their GP or community nursing team. Most people would prefer not to die in hospital, and in 2014/15, only 13% of people registered with Gold Line died in hospital (nationally this figure was 58%).

The Gold Line is being evaluated and has already seen very positive results, especially from people in their last year of life and their carers. Results of a financial evaluation are expected soon.

http://www.health.org.uk/gold-line

15.2.1 Film - Gold Line: Bringing health care home

Released on 27 November 2015 by the Health Foundation, this film explains how the Gold Line works with HCPs and carer contributions.

15.3 Transforming your palliative care and EoL care progamme

A 2 year programme designed by Marie Curie and the Health and Social Care Board (HSCB) (2013) running in Northern Ireland (NI) is running until 2015 and aims to work with key stakeholders to design and support the delivery of effective palliative and EoL care that facilitated peoples' preferred place of care. It is based on a whole systems approach to focus on localised and sustainable solutions, which addressed barriers across the entire system of palliative and EoL care service delivery

A total of eight initiatives comprise the programme. These priorities are the result of extensive engagement with a wide range of stakeholders during this first phase of the programme.

- Support for patients and carers
- Enhanced access to palliative care services at home
- Supporting planned discharge and provision of equipment

- Identification and planning for people with palliative care needs
- Training for healthcare providers
- Day hospice
- Ambulance service
- Palliative pharmacy

The programme includes three key phases:

Phase 1 – Collating and analysing data, talking to key stakeholders including patients and health and social care professionals, and identifying key areas for improvement in line with local priorities.

Phase 2 – Developing proposals to improve care.

Phase 3 – Implementing improved service design.

This programme places the person with palliative and End of Life Care needs at the centre, with the aim to be informed by, and to involve, those who need care, and their families and carers.

Health and Social Care Board (HSCB) (2015) Transforming your Palliative and End of Life Care.

http://www.transformingyourcare.hscni.net/tyc-in-action/palliative-and-end-of-life-care/

See also:

National Consensus Project for quality palliative care (2013). Clinical practice guidelines for quality palliative care. 3rd edition. www.nationalconsensusproject.org

15.4 Northern Ireland: National Clinical Programme for Palliative Care

This programme was established in Northern Ireland in 2010 as a joint initiative of the HSE Clinical Strategy and Programmes Division and the Royal College of Physicians. The programme aims to ensure that persons with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis.

Contact:
Clinicalprogrammeadmin@rcpi.ie
http://hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme

15.5 Doulas and Volunteers

In accordance with the drive to devolve responsibility for the NHS to local organisations based on local needs, the Department of Health lays great emphasis on local health and social care communities, and voluntary and professional organisations to take responsibility for leading and contributing to service change and improvement including End of Life Care.

Phase 2b of this EBS identified evidence about End of Life Doulas as constituting an innovative Advanced Nursing service. (Please see p27 of this document). “Carers’ Befriending Services” were also examples of Good Practice (p65) as was the idea of “Developing training for supporters of Lay carers involved with home based end of life care” (p67). Further research is advocated to ensure that the valuable contribution of *volunteers* in palliative care is used appropriately and effectively. A recent review found that volunteers in palliative care settings, including home settings, hospitals and nursing homes, resulted in families being significantly more satisfied with care and with patients surviving significantly longer if they had received home visits from a volunteer. However, to date none of the studies reviewed examined patient and family well-being and the potential disadvantages or adverse effects of volunteer involvement .

15.5 EoL Doula foundation training: Dying matters

This five day foundation course is the first part of the full 21 day end of life doula training. Themes covered include:

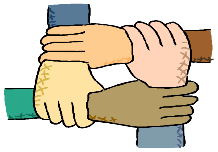
- understanding grief
- emotional and spiritual responses to death
- physical changes at the end of life
- palliative care
- increasing comfort and supportive therapies
- rituals and practices within cultural and faith groups
- socio-legal requirements
- communication

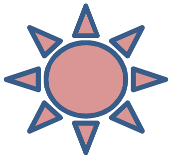
- the soul’s journey
- spiritual and self-care practices

http://dyingmatters.org/event/end-life-doula-foundation-training

16. EoL care planning and support – Written resources

Table 71 EoL planning and support - Written resources

<table>
<tr><td colspan="3">Preferred priorities for care: patient help document
This is designed to facilitate patients' choices in relation to End of Life issues. It documents their choices and this information can be shared with HCPs.
www.dyingmatters.org.gp
(click on section "how to help your patients plan")
Planning for your future care – a guide.
Explains advance care planning outlining different available options.
www.dyingmatters.org</td></tr>
<tr><td>

★★</td><td>Supporting a person who needs palliative care: a guide for family and friends
Authors: Associate Professor Peter Hudson, Director of the Centre for Palliative Care, Professor (Hon) at the University of Melbourne, and Dr Rosalie Hudson, a nurse educator in palliative care, aged care, dementia care, ethics and pastoral care.
Hudson P & R (2012) 2nd Edition.
Publisher Palliative Care Victoria,</td><td>This 84 page booklet would be invaluable for carers unless they had reading difficulties and/or English was not their first language. It can be dipped into according to need and covers the whole caring process from the identification of carer status to the death of the patient. Being an Australian production, it also addressed BAME issues. This would be a resource worth purchasing by PCFT.
It was developed using an evidence multi-disciplinary base and co-designed with carers. The use of the guidebook has also been evaluated in several research studies as part of a broader strategy aimed at enhancing family carer support. Although the original edition was aimed at carers of adults with cancer being cared for at home, most of the content remains relevant for people in a variety of settings and for those who are confronted by other life threatening illnesses.
This new edition includes updated information about these broader</td></tr>
</table>

<table>
<tr>
<td></td>
<td>© Copyright Palliative Care Victoria
ISBN 978-0-9580879-4-0
Free downloadable copy
http://www.pallcarevic.asn.au/families---patients/help---available/new---guidebook---for---carers/</td>
<td>contexts for palliative care, including those in aged care homes (also known in Australia as aged care facilities).
The chapters are as follows:
• Being a family carer: what's it all about?
• Caring for yourself and your relationships
• Caring for your relative at home
• Practical care
• Caring for your relative in hospital, hospice or aged care home
• Advance care planning, legal issues and funerals
• Care as death approaches and bereavement
• What resources are available?</td>
</tr>
<tr>
<td colspan="3">"Difficult conversations. Making it easier to talk to people with heart failure about the end of life

The National Council for Palliative Care, Dying Matters
Funded by British Heart Foundation
Aimed at exploring people's hopes, wishes and fears for the future. Although this was written for those caring for people affected by Heart Failure first and foremost and including all HCPs and, potentially, carers, it is relevant for COPD and of use to general carers of people at the End of Life.
http://shop.ncpc.org.uk/public/document/library.aspx?page=2&</td>
</tr>
</table>

Table 8 Other areas to consider

Transitions - Dealing with uncertainties - Fluctuating illness trajectories. - Difficulties in prognosis Recognising and coping with approaching death	**Sue Ryder, Hospice UK, NCPC** ***What to expect when someone important to you is dying. A guide for carers, families and friends of dying people*** This document is excellent and clearly maps out the dying process for lay people in a sensitive manner and in a very accessible format. It poses and answers questions lay carers may ask. In addition, there are some pages giving more formal advice on the whole process and End of Life trajectory. Altogether a very good resource. http://www.ncpc.org.uk/sites/default/files/What_to_Expect_FINAL_WEB.pdf **Hospice UK** ***Information resources on disease process, trajectory and prognosis. Information about the dying process and symptom management*** http://www.hospiceuk.org/what-we-offer/clinical-and-care-support/family-and-carers
Nursing skills - Suction, swallowing - Positioning techniques - Catheter care - PEG medications - Injecting and giving breakthrough medications - Hydration	**Hospice UK** Recommends for carers, 'information, training or education' on how to provide specific care tasks http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **NHS End of Life Care;** Managing pain and other symptoms Deals with other symptoms such as nausea, vomiting, loss of appetite and constipation www.nhs.uk/Planners/end-of-life-care/Pages/controlling-pain-and-other-symptoms.aspx Nursing skills acquisition training Managing breakthrough subcutaneous injections & Just in Case Boxes. See below page 147 **Macmillan. Hello and how are You? A guide for carers by carers** Section on personal care http://be.macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf

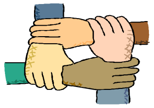
16.1 Film resources for EoL planning

Table 9 Film resources for EoL planning

Soulmate Knowledge about the implications of terminology in order to make decisions about a care plan/pathway http://www.patientvoices.org.uk/flv/0377pv384.htm		
Seven films from Dying Matters		
	• Dying to Know • We are Living Well but Dying Matters • A Party for Kath • Why Dying Matters to Me • How Long Have I Got, Doc? • Time to talk, Doc? • I didn't really want that http://dyingmatters.org/page/order-dying-matters-dvds	
Four films From SCIE (detailed)		
✡ ☀	**End of life care: why talking about death and dying matters** 10 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=endoflifecarepe	For people moving towards the End of Life a personalised approach gives them a voice and influence over their care. This film looks at how personalised care can be achieved through the Living Well tool, which involves creating a simple one page profile to record a person's needs and wishes. It is shared by everyone involved in their care so that they can quickly get to know and understand the person, even if they have communication difficulties. The film shows how the scheme is used in settings in **Stockport and in Hull** and features case studies showing how profiles work successfully in practice. Messages for practice

	rsonalisation	Personalised care for people at the end of life requires a planned and coordinated approach to care. Recording the likes, dislikes and preferences of a person at the end life in one place is a simple but important step towards achieving personalised care, whether from health or social care services. People who receive care which reflects what's important for them helps to make them feel more in control and more secure. An understanding of what's important for a person at the end of life means staff will have better ideas of how to support and reassure them. A simple tool which records people's preferences is also useful if they have to change care setting and can facilitate better working between health and social care.
✡ ✡	**End of Life and palliative care: thinking about the words we use** 4 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=palliative-care-or-end-of-life-care	The film uses animation and vox pops to make the case for practitioners to communicate how much they care about the person who is dying; as well as being clear about what they're doing to help and support the person and their friends and relatives. Practitioners need to ask themselves whether the words they are using convey this compassion, and also check with those they are caring for, that the information they are providing is clear as well as compassionate. **Messages for practice** • When speaking to a person who is dying or their relatives, understand the impact of the terms used • Where possible, try to explain things in plain English, rather than automatically using potentially unfamiliar terms like 'palliative' and 'end of life' care' • Regardless of the terms used, always check what the person has understood from the conversation • Always speak in a kind and caring way to the person who is dying as well as to their relatives and friends. **APPRAISAL** Although this film is for HCPs primarily, it would be useful to go through with a patient and their family in order to initiate discussion and clarification of terminology used in the End of Life in the context of CVD.
	End of life care: dying at home	In this film a palliative care social worker is interviewed about the skills and understanding that are needed to make sure people can die with dignity and respect. It shows members of the support team in Lancashire discussing care preferences with a man at the end of life and then making sure the practical services he needs are in place.

★	11 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=dyingathome	This film also features the Majlish Home Care Service in East London, which provides culturally-appropriate services to people in the Bangladeshi and Bengali communities who choose to die at home. The care workers employed are all from the same communities as the people they work with.
★★	**End of life Care: What matters to the person who's dying** 11 minute film http://www.scie.org.uk/socialcaretv/video-player.asp?v=holisticassessment	A palliative care specialist nurse from St Joseph's Hospice, London, defines holistic assessment as an on-going process involving the physical, social, psychological and spiritual care of a person at the End of Life. Through an interview with a woman with a chronic health condition, holistic assessment is shown working in practice; we see how she is supported to develop a plan which states her wishes about her End of Life care. This provides clarity for the family of the person as well as her health and social care team. There is also an interview with a woman who was initially reluctant to make plans about her End of Life care but, with the help of a social worker, has now done so and feels more confident and in control because she feels supported. **Messages for practice** • Holistic assessment is about the physical, social, psychological and spiritual needs of a person at the *EoL*. • Holistic assessment can result in a plan which records the wishes and decisions of a person at the *EoL*. This may be useful for family and everyone involved in their care. • Holistic assessment is an on-going process which can be updated and changed as the person's choices and preferences change. • The process of making a holistic assessment may increase the confidence and trust of a person at the *EoL*
♻ ★★ ☀	**GREATER MANCHESTER RESOURCE. BAME: Through our eyes** Just released, this is a DVD resource which includes excerpts of interviews with volunteers from Afro-Caribbean, Hindu, Jewish, and Muslim communities, talking about their experiences of end of life care for a loved one. This film was the result of Palliative and End of Life Care Network in collaboration with Stories to Change, CIC and launched on 1st April 2015. A Summit brought together communities, commissioners, managers and care staff to showcase the premier of this film. Volunteers helped create the film and supported key discussions which will support the development of guidance to improve End of Life Care. A key aim of the whole project is to ensure that people involved in End of Life Care including care of the	

	dying person, are able to do so in a way that meets cultural, religious and personal expectations. The film can be used as a resource for community and faith groups and to help inform NHS professionals. It describes how the care offered in the last days of life can have a profound effect on those left behind. **APPRAISAL** This is a new resource recently developed by the Greater Manchester. The film has a sound grounding due to including the views of lay ‘experts’ in the field. A booklet to accompany the film is in development. A copy has been given to MHMC, PCFT Further copies can be obtained from, denise.woolrich@nhs.net www.gmiscscn.nhs.uk/index/php Please note. The use of this film involves a short evaluation exercise in order to assist with the development of the guidance pack. This is accessed via Https//www.surveymonkey.com/r/59GPDJK

✡

No greater gift

In *No Greater Gift* you will hear from past and current carers who have undertaken this important role on a variety of levels with the support offered to them by palliative care. They share their unique and personal stories in the hope that others will benefit from their experience.

No Greater Gift is suitable for individuals and their families who are embarking on the carer role. It can also be used to generate discussion during a support group or counselling session.

NB: Viewers are cautioned that Part 2 – End of Life and Bereavement contains detailed accounts of End of Life planning and reflections on the grief experience.

The MHMC team and Pennine Care NHS Foundation Trust have a copy of this DVD

Developed by:
The Centre for Palliative Care, St Vincent's Hospital and Collaborative Centre of The University of Melbourne
The Carer/Consumer DVD Steering Committee
Funded by: The Victorian Cancer Agency, Department of Health, Melbourne, Victoria

DVD produced by: Educational Resource Centre, The Royal Children's Hospital
For a copy of the DVD please call +61 3 9416 0000 or email centreforpallcare@svhm.org.au

http://centreforpallcae.org/resources/hospital-based-group-education-program/resources-for-the-hospital-based-group-education-program

APPRAISAL

Although most of the films above (apart from “Through our eyes”) are intended primarily for HCPs, it is considered that they may be very useful for patients, carers and HCPs to watch together - with the families’ permission regarding their content. They are short and accessible using real patients, carers, case studies and HCPs in order to put across salient points.

17. Clarifying terminology for carers

An issue for patients and carers, especially BAME carers, is understanding the terminology used by HCPs. This issue has been flagged up in earlier stages of the EBS. Recent evidence shows that this is a potential barrier to the uptake of palliative care, some carers interpreting EoL care preferences as a question about euthanasia or suicide. Misunderstandings and myths regarding various terms need unraveling and avoiding the use of professional jargon or terminology could significantly improve people's understandings of care available.

The box below contains terms and description familiar to HCPs the meanings of which can then be transmitted to COPD patients and their carers. As mentioned above, other terminology such as those used in lifestyle advice should also be explained.

The definition adopted in this document of the term 'end of life' is that used by the General Medical Council, that is, where death is expected within 12 months. This definition includes people with advanced, progressive, incurable conditions.

http://www.nice.org.uk/guidance/qs13/chapter/quality-statement-1-identification

EoL is recognised as being one component of palliative care and concerned with a 30 day period and because things like stroke, for example, can be a sudden event .

EoL care helps those with advanced, progressive, incurable illnesses such as heart failure, to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (The Princess Royal Trust, 2010).

There is a national drive to improve the quality of EoL care in all clinical areas. Encouraging collaboration and partnership when working with specialist palliative care services would optimise palliative care service delivery and may provide patients and their families with greater opportunities for documenting and achieving preferences for care and achieving a better quality of death.

The National Council for Palliative Care describe EoL care as care that helps all those with advanced, progressive and incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

The World Health Organisation defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems 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.” Another nice definition cited in, Ward et al, (2014) is, “care for people of all ages with a life limiting condition” http://www.healthpages.co.nz/health-topics/where-to-go/palliative-services-dying.

Palliative care looks to address physical, emotional, spiritual and social concerns of patients who have advanced illnesses and those around them. It is a specialist branch of healthcare that instead of focusing on active interventions and treatments intended to prolong life it focuses on symptom relief and support to manage the stress and impact of serious illness for someone with a life limiting illness[42]. Palliative care looks at providing relief from physical aspects of life limiting illness. These may be many distressing physical symptoms. Emotional, spiritual and psychosocial issues are also addressed. Palliative care can provide support systems for family to help them cope, such as offering respite whilst caring for the patient. On-going support will preserve a good quality of life for both patients and their families .

Routes to symptom management are various depending on the patient. A lot of medication may be given subcutaneous that is injected under the skin as opposed to the patient swallowing this. Palliative care asserts that dying is a natural process, and addressing aspects of death that are important to the individual are examined. This could be around where the person wants to die, whether they want active treatment to stop or continue. Palliative care does not do anything to either hasten or postpone death. It is not euthanasia or assisted death and does not prolong life through artificial intervention.

Palliative care is multi-disciplinary and a whole team makes up the palliative care approach in caring for a patient and their family. This includes doctors and nurses, social workers, counsellors, Chaplaincy, pharmacists and a variety of other allied health care professionals. Factors that are addressed include loss of independence, financial insecurity, worries about the future and/or impact of feeling like a burden. Palliative care is the treatment of ‘total suffering’ or ‘total pain’.

The philosophy of palliative care is to achieve the best quality of life, throughout the disease trajectory for the patient and their family, by providing relief and preventing suffering. However, some carers are not aware of the phrase and its meaning but become open to the suggestion when they understand what it would mean to their family member’s care..

“Hospice” - facilities or services which are especially devoted to providing palliative and supportive care to the patient with a terminal illness and to the patient's family .

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[42] *A life limiting or threatening illness means a patient is in the last 6 – 12 months of life.*

18. One-to-One nursing skills acquisition courses for carers

The following two programmes are included the General End of Life EBS. However, they are also described here because they could be relevant for COPD care at the end of life for family carers at home.

18.1 An educational package to support lay carers to manage breakthrough subcutaneous injections. Development and evaluation of a service quality improvement[43]

18.1.1 Abstract (abridged)

Palliative care services strive to support people to live and die well in their chosen environment, with optimal symptom control and a pattern of care supportive of laycarers. The likelihood of patients remaining at home often depends upon laycarers, who may be required to manage subcutaneous medications. Structured education programmes for laycarers result in positive patient and laycarer outcomes relating to symptom management, provide laycarers with the knowledge to understand the rationale of good symptom management and adds to their confidence in administering the right drug for the right symptom at the right time. This generates improved patient outcomes and decreases unwanted and inappropriate admissions to acute care facilities. There is some literature confirming the ability of laycarers to successfully administer pre-prepared syringes for symptom control, but few studies concern themselves with the practice of also teaching laycarers to prepare these injections.

There is resistance from some palliative care service providers about the appropriateness of teaching laycarers to prepare and administer subcutaneous injections in part due to the perception that the task is too burdensome for family members. In addition, there is organisational and individual uncertainty related to legal, jurisdictional and scope of practice issues for registered nurses and laycarers.

This study reports on the development, trial and evaluation of a package that teaches laycarers to manage subcutaneous medications used for symptom control in home-based patients. The package was developed by palliative care stakeholders and comprises an educational session, delivered by nurses, and a range of demonstrative, audiovisual and written resources. It was trialled across 24 sites and was finally evaluated

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by 76 laycarers (pre and post-use) and 53 nurses. Laycarers and nurses rated the usefulness and relevance of the package highly – all ratings were above 5 on a 7-point scale. The study is described below.

Table 10 An educational package to support lay carers to manage breakthrough subcutaneous injections

BACKGROUND TO PACKAGE	**DELIVERY OF PACKAGE**
The package was developed by palliative care stakeholders It is suitable for delivery in a one-on-one format in the laycarer's home It can be implemented across various health and geographical settings Different teaching materials and modalities allow for individual differences in rates and style of learning. 76 laycarers and 26 nurses highly rated the usefulness and relevance of the package.	An education session delivered by nurses with a range of demonstrative, audiovisual and written resources that educated and supported laycarers to competently and safely: • prepare, store and administer subcutaneous injections • to monitor subcutaneous sites • to manage a medication administration record suitable for easy assessment by health professionals • to understand the uses of common medications used in palliative care. The education session required between 20 and 60 minutes to complete and was used to introduce the suite of 8 resources developed for the study. The session included: • Standardised information content, focusing on safety, competency and skills (inclusive of preparation, storage and administration of breakthrough injections) and deliverable by registered nurses to lay carers. • A training manual was developed to guide clinically registered nurses in the delivery of the education session. A suite of resources was developed for use within the education session and to provide lay carers ongoing support in their day-to-day management of subcutaneous medications. All the materials produced by this study can be accessed via http://www.caresearch.com.au/caresearch/tabid/2145/Default.aspx

18.1.2 Feedback on the package

Lay-carers perceived the overall usefulness of the package as soon as they had completed their one-on-one education session. This perception was maintained after they had had the experience of symptom management using subcutaneous medications. They were satisfied that the package information was relevant to them and the content provided necessary technical skills to manage subcutaneous medications. Importantly, they felt confident that they could safely pre-prepare and inject subcutaneous medications. In addition, the package decreased their stresses surrounding subcutaneous injections and they were satisfied that they could assist with symptom management. The package, by allowing access to standardised and relevant information, empowers lay crers to care safely for loved ones at home.

Nurses rated the education session highly for aspects such as appropriateness to the needs of lay-carers, providing the necessary information to allow lay-carers to safely pre-prepare and administer subcutaneous injections. Similarly, they indicated that the issues relevant to subcutaneous injections of palliative care medications had been well explained and the components of the package provided useful resources for lay-carers.

Nurses felt that the education session was easy to deliver, adequately explained injecting issues and recommended its continued use. Notwithstanding this, delivery of the standardised education challenged some nurses, possibly because it encompassed practice change. Clinical opinion varied as to the appropriate time in the patient's palliative care trajectory to present the education session. The consensus was that the time for package introduction depended upon each particular clinical situation and laycarer. Some commented on the clinical load imposed due to the time required to deliver the session depending upon the clinician and individual lay-carers' abilities and learning styles. They concurred however, that with continued experience in education delivery, the time required to introduce the package would decrease.

Nursing opinion was divided concerning whether it is safe and appropriate for laycarers to manage subcutaneous injections.

Some nurses reiterated their concerns about safety issues related to lay carers managing symptoms and the burdensomeness of that task. However, given lay carers' high level of satisfaction with the package, it may be that nurses, and other health-care professionals, have been overprotective or gatekeeping in their attitudes to lay-carers.

The package showed that lay-carers can learn to manage subcutaneous injections, thus contributing to breakthrough symptom control in a timely and effective way. It is likely that use of the package can contribute to more patients being able to die in the environment of their choice, their home. Potentially, this will result in an improved quality of death and decrease the cost burden to the health-care system incurred when distressed patients are unnecessarily transferred to acute care facilities. If the ability of lay-carers to provide symptom management is improved by initiatives such as the package described here, then the capacity of professional palliative care staff, particularly nurses, to care for more people will be enhanced.

18.1.3 Safe practice measures[44]

The issue of safe practice was a fundamental consideration throughout the package development. To reinforce written medication information, a colour coding system, adapted from anaesthetic drugs safety standards and advocated by an Australian national labelling project, helped lay-carers to identify correct medications, and avoid errors, through the use of labelling pre-prepared syringes. The importance of the colour coding system was emphasised during the education session. Lay-carers were taught that they could use the coloured labels on the pre-prepared syringes as a cue to help distinguish between medications, even when they were tired or distressed. All the pre-prepared injections were stored in secure containers in the refrigerator. The fridge door magnet incorporated the colour-coding system, thus further consolidating the colour prompt for the lay-carer. The magnets were designed to be written on, so changes in medication could be easily updated by nurses or laycarers. The colour coding system was uniform across all package resources including the medication booklet and DVD.

Another safe practice measure was the diary provided to lay carers that encouraged the recording of every injection given as well as the effectiveness of the medication for symptom relief. This clinical tool proved to be of great value to both lay carers and visiting health professionals. Lay-carers experiencing a sense of security in having a record of injection administration as pressures associated with the caring role often led to an inability to accurately recollect medical detail. Indeed, most lay carers chose to continue using the diary even after study completion. Nurses reported that they could easily interpret the information contained within the standard diary and this helped them monitor medication effectiveness, progress of symptom evolution and patient condition.

18.1.4 Conclusion

This study demonstrates that if lay-carers are supported with education and resources, tailored to their needs, they can confidently, safely and competently manage breakthrough subcutaneous medications to relieve symptoms in home-based palliative care patients[45] .

18.2 Audit of the use of ‘just-in case’ boxes as part of a Local Enhanced Service agreement for EoL care

This project links with the idea of carers being able to administer pain relief to patients in their own home when they need it.

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[44] *To clarify issues about the legal, jurisdictional and scope of practice issues related to the common palliative care practice of preparing subcutaneous injections and leaving them in the home for subsequent administration by lay carers the Brisbane South Palliative Care Collaborative prepared a document entitled Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland. This document has been endorsed by Queensland Health, Australia and complies with the Health (Drug and Poisons) Regulation 1996, the Queensland Powers of Attorney Act 19982, and the Guardianship and Administration Act 2000.*

[45] *Findings may not be directly applicable across all palliative care service populations. And this study is not applicable across countries due to differences in legal codes.*

18.2.1 Abstract (abridged)

Background: The local enhanced service for end of life care was started by Worcestershire Primary Care Trust in 2009, with the aim of developing good practice and improving EoL care. GPs were asked to sign up to and fully adopt the GSF. Access to palliative care medications and proactive management of symptom control are key components of GSF, and to support this ‘just-in case’ boxes were launched in April 2010. It was anticipated that the use of the boxes would avoid the distress caused by poor access to medications in out of hours, by anticipating symptom control needs and enabling availability of key medications in the patient’s home.

Outcomes: To assess the success of this initiative a 6 month audit was undertaken between May and October 2010.

Results: A total of 66 boxes were placed in patients homes. Fifteen of those boxes were not used. No patients were transferred into the acute trust (one patient was transferred to a care home), meaning that 65 people remained in their own home at time of death, with 48 of those patients’ EoL care being supported by provision of anticipatory medication. Only 6% of the responses reported any resistance to use of the boxes, either by the patient or their family. Provision of the boxes improved symptom control in 55% of the cases, and 89% of the boxes were reported as containing the most appropriate drugs. A cost saving of at least £69,140 was made. This was calculated by multiplying the number of times the provision of the just-in case box prevented use of a further healthcare service by the average cost for that specific episode of care. This can be compared favourably to the cost of providing the drugs which is around £3K.

NICE are proposing a cluster randomised controlled trial to compare “Just in case box” use with a generic list of medications or anticipatory prescribing individualised to the patient’s expected symptoms, compared with reactive prescribing at the bedside after symptoms have occurred. Outcomes of interest will include patient and carer symptom ratings, patient rated quality of life and healthcare use (NICE, 2015).

19. Final comments

Respiratory diseases including COPD are not clearly placed in the arena as needing palliative and EoL care and, as a non-malignant disease, COPD patients and carers have been recognised as not having their PC needs met. Family caregivers of COPD patients at the EoL are often physically and emotionally exhausted from years of stress and fatigue associated with the care-giving COPD rollercoaster. Even with the best available supports, dying at home from end-stage COPD may not be realistic or even the best option for some carers. However, there is now a general shift towards ensuring that all patients with life limiting conditions receive appropriate palliative care services based on their level of need, and not their diagnosis - from the point of their diagnosis and continuing throughout the disease trajectory.

PR is key for COPD patients and carers and CBT and Psychology can increase completion rates for PR as seen in the interventions at The Hillingdon and Whittington Hospitals, London and a number of other COPD services. Professional and lay Doulas also been evidenced in the literature as a potential resource to support family carers and this idea has been identified elsewhere in this seriesof EBSs.[46]

This EBS has noted available support programmes for COPD patients and carers and the developments towards pathways for COPD patients.

Dr Valerie Featherstone,

Also, thank you to the many health care professionals and researchers for their support to VF in gathering information for this EBS

December 2015

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[46] *Lay and professional Doula training has been explored in Phase 2b, "EDUCATION AND SUPPORT FOR CARERS AT THE END OF LIFE" with several examples of good practice being described.*

Appendix 1. Evaluation of the SAGE & THYME® ACP workshop.

Executive Summary

1. The ‘SAGE & THYME for advanced care planning and end of life conversations’ (S&T ACP) workshop aims to teach participants how to structure a conversation, using the S&T ACP model. This model was developed to aid discussion of ACP issues and deal with concerns raised by patients/carers. It was developed by University Hospital of South Manchester NHS Foundation Trust (UHSM) in collaboration with Lancashire and South Cumbria Cancer Network.
2. 22 workshops were run across 8 locations between December 2012 and May 2014.
3. 413 participants attended the workshop and 91% completed pre and post workshop questionnaires.
4. 31% of participants were GPs, 48% came from a variety of healthcare professions (e.g. practice nurse, community matron). 88% of the participants were female and the vast majority (88%) had qualified since 1980.
5. The median case load was 88, with a wide range from 1 to 16000. 31% said that under a tenth of their case load were patients in the last year of their life, and another 34% said that over 50% of their patients were in their last year.
6. Over the last 3 months the majority of participants had had between 1 and 5 ACP conversations
7. Over the last 3 months between 24% and 26.3% of participants had avoided 1 or more ACP conversations, due to lack of confidence, or other reasons.
8. There was a significant increase from pre- to post-workshop in the level of confidence participants had in starting an end of life or advanced care planning conversation (rated from 1-10). Median increase of 2, range -2 to 7, n=381, p<0.001.
9. There was a significant increase from pre- to post- workshop in the level of confidence participants had in responding to a patient’s or relatives concerns during an end of life or advanced care planning conversation (rated from 1-10). Median increase of 2, range -3 to 7, n=378, p<0.001.
10. There was a significant increase from pre- to post- workshop in the level of perceived competence in conducting an advanced care planning conversation (rated from 1-10). Median increase of 2, range -2 to 8, n=376, p<0.001.
11. When asked ‘how likely are you to use the SAGE & THYME model in your practice?’ (rated from 1-10) the median score was 9 (range 1-10)
12. 74% of participant’s said they would definitely change their practice as a result of the workshop. 21% said they possibly would.
13. 88% of participants would definitely recommend the workshop to their colleagues. 11% possibly would.
14. In conclusion, the SAGE & THYME ACP workshop significantly increased participant rated confidence and perceived competence in conducting ACP conversations. Participants were highly likely to implement what they had learnt into their own practice.

27th August 2014. Report written by: Joel Coppeard (pp. 3-4)

References

Aqua Analytics (2014). COPD care in the North West of England. NHS.

Contact. anthony.mather@srft.nhs.uk

Al-Gamal, E., & Yorke, J. (2014). Perceived breathlessness and psychological distress among

patients with chronic obstructive pulmonary disease and their spouses. *Nursing and Health Sciences, 16*, 103–111.

American Thoracic Society Documents (2008). An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses. Am J Respir Crit Care Med, 177. pp 912–927.

DOI: 10.1164/rccm.200605-587ST

Internet address: www.atsjournals.org

Barnes, S., Gardiner, C., Gott, M., Payne, S., Chady, B., Small, N., Seamark, D., & Halpin, D. (2012). Patient-Professional Communication About End-of-Life Issues in Life-Limiting Conditions: A Critical Review of the Literature. *Pain and Symptom Managemen*t, *44*,6.

Barker, D., Davies, C., Dixon, B., Hodgson, A., Reay, S., Barclay, N. (2014). Training community matrons in basic cognitive behavioural therapy-based techniques for patients with COPD. *Br J Community Nurs*, *19,* 274–283.

Barroso, J., and Gollop, C.J. (2003). "The Challenges of Searching for and Retrieving Qualitative Studies." *Western Journal of Nursing Research, 25, 2,* 153 -178.

Beernaert, K., Cohen, J., Deliens, L., Devroey, D., Vanthomme, K., Pardon, K.,Van den Block, L. (2013). Referral to palliative care in COPD and other chronic diseases: A population-based study. *Respiratory Medicine, 107,* 1731, e1739.

Beernaert, K., Deliens, L., Pardon, K., Van den Block, L.,Devroey, D., Chambaere, K. (2015). What Are Physicians' Reasons for Not Referring People with Life-Limiting Illnesses to Specialist Palliative Care Services? A Nationwide Survey. *PLoS ONE 10. 9,* e0137251.

doi:10.1371/journal.pone.0137251

Booker, R. (2010). Improving outcomes in COPD. Published as a Supplement to *Practice Nursing,Vol. 21*.

Booth, S. (2013). Science supporting the art of medicine: improving the management of breathlessness. *Palliative Medicine, 27, 6,* 483–485.

DOI: 10.1177/0269216313488490

Bove, D., G., Overgaard, D., Lomborg, K., Lindhardt, B. O., Midtgaard, J. http://bmjopen.bmj.com/content/5/7/e008031 - aff-5 (2015). Efficacy of a minimal home-based psychoeducative intervention versus usual care for managing anxiety and dyspnoea in patients with severe chronic obstructive pulmonary disease: a randomised controlled trial protocol. *BMJ Open, 5,* e008031.

doi:10.1136/bmjopen-2015-008031

British Thoracic Society (2011). How to improve quality and productivity by integrating COPD care, British Thoracic Society Reports, 3, 1.

http://www.impressresp.com/index.php?option=com_docman&Itemid=82#sthash.3WTWy3EP.dpuf

Brown, J. (2014). Improving care for COPD: Implementing
NICE Quality standard 10, Statement 10

Report commissioned by North East Quality Observatory System on behalf of the Collaborating for Better Care Partnership.

http://www.ahsn-nenc.org.uk/wp-content/uploads/2015/05/COPD-palliative-NICE-QS1013-v1-final.pdf

Accessed 7/10/16.

Candy, B., France, R., Low, J., Sampson, L. (2015). "Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence." *Int J Nurs Stud*, *52, 3,* 756-768.

Clark, D., M. (1986). A cognitive approach to panic. *Behav Res Ther, 24,* 461–470.

Cecchino, N. J., (2010). Electronic resource review: Google scholar. *Journal of the Medical Library Association*, 98, 4, 320–321.

Connolly, M., Beattie, J., Walker, D., and Dancy, M., (2014). End of Life Care in Heart Failure. A framework for implementation. NHS Improving Quality. www.nhsiq.nhs.uk

Cowey, E., Smith, L., N., Stott, D., J., McAlpine, C.H., Mead, G. E. D., Barber, M.,& Walters, M. (2015). "Impact of a clinical pathway on end-of-life care following stroke: a mixed methods study." *Palliat Med*, *29. 3,* 249-259.

Crawford, G. B., Brooksbank, M. A., Brown, M., Burgess, T. A,. & Young, M. (2012). Unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia. *Internal Medicine Journal,* 43, (2):183-90

doi:10.1111/j.1445-5994.2012.02791.x

Cottrell, E., Chambers, R., and O'Connell, P. (2012). Cardiovascular medicine. Using simple telehealth in primary care to reduce blood pressure: a service evaluation. *BMJ Open, 2*:e001391

doi:10.1136/bmjopen-2012-001391

Cruz, J., Marques, A., & Figueiredo, D (2015). Impacts of COPD on family carers and supportive interventions: a narrative Review. *Health and Social Care in the Community*.

doi: 10.1111/hsc.12292.

Currow, D. C., Farquhar, M., Ward, A. M., Crawford, G. B., Abernethy, A. P. (2011). Caregivers' perceived adequacy of support in end-stage lung disease: results of a population survey. *BMC Pulmonary Medicine*, *11,* 55.

Davidson, J., Baxter, K., Glendinning, C., & Irvine, A. (2013). Choosing health: qualitative evidence from the experiences of personal health budget holders. *Journal of Health Services Research & Policy. 18 (Suppl. 2),* 50–58.

DOI: 10.1177/1355819613499747

Department of Health. (2011). An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England.

http://www.dh.gov.uk/publications

Department of Health. (2012). COPD Commissioning Toolkit**.** *A Resource for Commissioners. Gateway reference **17874***

www.dh.gov.uk/publications

Department of Health. (2012). An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England – NHS Companion document.

file:///P:/COPD%20and%20end%20note%20library/Guidelines/Outcomes%20strategy%20for%20copd%20and%20asthma.pdf

Duenke, R. G. I., Heijdra, Y., Verhagen, S. C., Dekhuijzen, R., Vissers, K. C. P., & Engels, Y. (2014). PROLONG: a cluster controlled trial to examine identification of patients with COPD with poor prognosis and implementation of proactive palliative care. *BMC Pulmonary Medicine. 14,* 54.

http://www.biomedcentral.com/1471-2466/14/54

Edvardsen, A., et al, (2012) Air Travel and Chronic Obstructive Pulmonary Disease: A New Algorithm for Preflight Evaluation. *Thorax 67*, 964-969a

EAPC. (2010). "White Paper on improving support for family carers in palliative care: part 1 & 2. "*European Journal of Paliative Care",17, (5 & 6).*

Esteban, C., Arostegui, I., Moraza, J., Aburto, M., Quintana, J. M. J., Pe´rez-Izquierdo, J., Aizpiri, S., & Capelastegui, A. (2011) Development of a decision tree to assess the severity and prognosis of stable COPD. *Eur Respir J,* ***38,*** 1294–1300

DOI: 10.1183/09031936.00189010

Esteban, C., Quintana, J.M., Aburto, M., et al. (2006). A simple score for assessing stable chronic obstructive pulmonary disease. *QJM,* **99**: 751–759.

Ekström, M.P., Abernethy, A. P., Currow, D.C., (2015) The management of chronic breathlessness in patients with advanced and terminal illness. *BMJ,* 349:g7617

doi: 10.1136/bmj.g7617

Farquhar, M., Higginson, I., J., Fagan, P., & Booth, S. (2010). Results of a pilot investigation into a complex intervention for breathlessness in advanced chronic obstructive pulmonary disease (COPD). *Brief report Palliative and Supportive Care, 8,* 143–149.

doi:10.1017/S1478951509990897

Figueiredo, D., Gabriel, R., Jácome, C., Cruz, J., & Marques, A. (2014). Caring for relatives with chronic obstructive pulmonary disease: how does the disease severity impact on family carers? *Aging & Mental Health, 18, 3,* 385-393

doi.org/10.1080/13607863.2013.837146

Fitzsimons, D., McIlfatrick, S., and Taylor, B. (2015) Implantable cardioverter defibrillator(ICD) deactivation discussions: Realityversus recommendations. *European journal of Cardiovascular Nursing*, 1 .

Gabriel, R., Figueiredo, D., Jácome, C., Cruz, J., & Marques, A. (2014). "Day-to-day living with severe chronic obstructive pulmonary disease: towards a family-based approach to the illness impacts." *Psychol Health*, *29***,** *8,* 967-983.

Gardiner, C., Harrison, M., Ryan, T., & Jones, A. (2013). "Provision of palliative and end-of-life care in stroke units: a qualitative study." *Palliat Med*, *27, 9*, 855-860.

Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., Ruse, C., Seamark, D. (2010). Exploring the care needs of patients with advanced COPD: an overview of the literature. *Respir Med*, *104,* 2.

Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in Caregivers of Older Adults with Advanced Illness. *J Am Geriatr Soc. 58,* 2315–2322.

Garrow, A., Yorke, J., Khan, N., Vestbo, J., Singh, D., & Tyson, S. (2014). A systematic literature review of Patient Reported Outcome Measures (PROMs) used in the assessment and measurement of sleep disorders in Chronic Obstructive Pulmonary Disease. *Int J Chron Obstruct Pulmon D,* eScholarID:228834

Gautun, H., Werner, A., & Luras, H., (2013). Care challenges for informal caregivers of chronically ill lung patients: Results from a questionnaire survey. *Scand J Public Health, 2012 40,* 18.

DOI: 10.1177/1403494811425712

Grant, M., Cavanagh, A., Yorke, J. (2012). The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers' psychological well-being: A narrative review. *International Journal of Nursing Studies,49,* 1459-1471.

GOLD (2013)_ Global Strategy for the Diagnosis, Management and Prevention of COPD, Global Initiative for Chronic Obstructive Lung Disease. Updated 2015.

http://www.goldcopd.org/

Health Quality Ontario (2013). Action Plans for Individuals with COPD: A Rapid Review. January 2013; 20 p.

http://www.hqontario.ca/Portals/0/Documents/eds/rapid-reviews/action-plans-copd-130111-en.pdf

Health Quality Ontario (2015). Cognitive-behavioural therapy for anxiety and depression in patients with COPD: a rapid

review. Toronto: Health Quality Ontario; 2015 February. 21 p.

http://www.hqontario.ca/evidence/evidence-process/episodes-of-care#community-copd.

Heslop, K., Newton, J., Baker, C., Burns, G., Carrick-Sen, D., De Soyza, A. (2013). Effectiveness of cognitive behavioural therapy (CBT) interventions for anxiety in patients with chronic obstructive pulmonary disease (COPD) undertaken by respiratory nurses: the COPD CBT CARE study: *BMC Pulm Med, 13,* 62.

Healy, S., Israel, F., Charles, M. A., & Reymond, L. (2013). An educational package that supports laycarers to safely manage breakthrough subcutaneous injections for home-based palliative care patients: Development and evaluation of a service quality improvement. *Palliat Med,27, 6,* 562-570.

Hodson, M., Jennings, R., & Martin, J. (2011). The Breathing Space Clinic: A Pilot Study to Support the Holistic Needs of Patients WITH advanced. *BMJ Support Palliat Care, 2011, 1*, 204.

10.1136/bmjspcare-2011-000100.17

Horton, R., Rocker, G., Dale, A., Young, J., Hernandez, P., & Sinuff, T. (2013). Implementing a Palliative Care Trial in Advanced COPD: A Feasibility Assessment (The COPD IMPACT Study). *Journal of Palliative Medicine, 16*,*1.*

DOI: 10.1089/jpm.2012.0285

Horton, R., & Rocker G. (2010). Contemporary issues in refractory dyspnoea in advanced chronic obstructive pulmonary disease. *Curr Opin Support Palliat Care, 2010, 4, 2,* 56–62.

Howard, C., Dupont , S., Haselden , B., Lynch J., & Wills, P (2010). The effectiveness of a group cognitive-behavioural breathlessness intervention on health status, mood and hospital admissions in elderly patients with chronic obstructive pulmonary disease. *Psychology, Health & Medicine, 15 ,4*, 371-385.

DOI:10.1080/13548506.2010.48214

Howard C., & Dupont, S., (2014). 'The COPD breathlessness manual': a randomised controlled trial to test a cognitive-behavioural manual versus information booklets on health service use, mood and health status in patients with chronic obstructive pulmonary disease. *Primary Care Respiratory Medicine. 24,* 14076.

doi:10.1038/npjpcrm.2014.76

Hudson, P.L., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., Hall, C., Trauer, T., Bolleter, A., Clarke, D.M., and Bauld, C. (2012). Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *Journal of Palliative Medicine. 15, 6*, 696-702.

doi:10.1089/jpm.2011.0466.

Hudson, P. L., Trauer. T., Lobb, E. A., Thomas, K (2012). "Supporting family caregivers of hospitalised palliative care patients: a psychoeducational group intervention." *Supportive and Palliative Care, 2, 2,* 115-120.

Huttmann S., Windisch, E., Storre, W., Hendrik, J. (2015). Invasive Home Mechanical Ventilation: Living Conditions and Health-Related Quality of Life. *Respiration, 89,* 312–321.

DOI: 10.1159/000375169

Isis, E., van Gennip, H., Roeline, W., Pasman, P. J., Kaspers, M. G., Oosterveld-Vlug, D. L., Willems, D. J. H., Deeg, B. D., Onwuteaka-Philipsen. (2013). Death with dignity from the perspective of the surviving family: A survey study among family caregivers of deceased older adults. *Palliative Medicine. 27, 7,* 616–624.

DOI: 10.1177/0269216313483185

Janssen D. J., Wouters, E.F. M., Spruit, M. A. (2015a). Psychosocial consequences of living with breathlessness due to advanced disease. *Curr Opin Support Palliat Care, 9*, 232–237.

doi:10.1097/SPC.0000000000000146.

Janssen, D. J. A., van den Bogaart, E. H.A., Wouters, E. F., Franssen, F. M .E., Vercoulen J. H., & Spruit M. A. (2015b). Informal caregivers of patients with COPD: Home Sweet Home? *Eur Respir Rev, 24,* 498–504.

DOI: 10.1183/16000617.00010114

Kehl, K. A. (2015). "How hospice staff members prepare family caregivers for the patient's final days of life: an exploratory study." *Palliat Med, 29,2,* 128-137.

King, N., Brooks, J., Featherstone, V. A., & Topping, A. (2014). Supporting people with active and advanced disease: a rapid review of the evidence. *Project Report*. University of Huddersfield, Huddersfield, UK.

This version is available at http://eprints.hud.ac.uk/19674/

Kitzinger K and Wilkinson, S (2015). A matter of life and death. *The Psychologist, 28*, 12, 972-975

Leventhal, I.I., Meyer, D., Nerenz, D.R. (1980) The Common Sense Representations of Illness Danger. In Rachman S (ed.) Contributions to Medical Psychology. Pergamon: New York, 1980, 17–30.

MacPherson, A., Walshe, C., O'Donnell, V., & Aashish, V. (2012). The views of patients with severe chronic obstructive pulmonary disease on advance care planning: A qualitative study. *Palliative Medicine,* 27, 3, 265–272.

DOI: 10.1177/0269216312440606

McDonald, C. F., & Khor, Y. (2013). "Advances in chronic obstructive pulmonary disease." *Intern Med J, 43, 8,* 854-862.

McGuire, D. B., Grant, M., & Park, J. (2012). Palliative care and end of life: The caregiver. *Nursing Outlook, 60, 6,* 351-356. http://dx.doi.org/10.1016/j.outlook.2012.08.003.

Mentes, J., & Kang, S. (2013). "Evidence-Based Practice Guideline Hydration Management." *Journal of Gerontological Nursing, 39, 2.*

Momen, N., Hadfield, P., Kuhn, I., Smith, E., Barclay, S. (2012).Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis.

doi:10.1136/thoraxjnl-2012-201835

Nakken, N., Janssen, D. J .A., van den Bogaart, E. H. A., Wouters, E. F.M., Franssen, F. M. E., Vercoulen, J. H., & Spruit, M. A. (2015). Informal caregivers of patients with COPD: Home Sweet Home? *Eur Respir Rev, 15, 24,* 498–504.

DOI: 10.1183/16000617.00010114

NHS Scotland. (2010). End of life care following acute stroke. Best Practice Statement, NHS Quality Improvement Scotland .

file://nask.man.ac.uk/home$/Downloads/BPS_ENDOFLIFESTROKE_DEC10.pdf

NHS. (2011). NHS Improvement - Lung National Improvement Projects - Improving end of life care in chronic obstructive pulmonary disease (COPD): testing the case for change.

NHS. (2012). Chronic obstructive pulmonary disease: Evidence Update February 2012 .A summary of selected new evidence relevant to NICE clinical guideline 101 'Management of chronic obstructive pulmonary disease in adults in primary and secondary care' (2010).

Nauser J. A., Bakas, T., Welch J. L. (2011). A New Instrument to Measure Quality of Life of Heart Failure Family Caregivers. *Journal of Cardiovascular Nursing, 26,1*, 53-64.

NICE. (2010). Chronic obstructive pulmonary disease: management of chronic obstructive pulmonary disease in adults in primary and secondary care. London: National Clinical Guideline Centre.

http://guidance.nice.org.uk/CG101/Guidance/pdf/English

NICE. (2011). Chronic obstructive pulmonary disease (updated) CG101: full guideline.

https://www.nice.org.uk/guidance/cg101

NICE. (2015). Care of the Dying Adult. Clinical guideline. Methods, evidence and recommendations. Draft for consultation.

National Clinical Guideline Centre.

http://www.nice.org.uk/guidance/NG31/documents/care-of-the-dying-adult-full-guideline2

O'Driscoll. R., Caress, A., Backerly, N., Roberts, J., Woodcock, A.,Yorke J. (2015). A study of attitudes, beliefs and organizational barriers related to safe emergency oxygen therapy for patients with COPD in clinical practice and research. *B M J Open Respiratory Research,* eScholar ID:274772

Oishi, A., & Murtagh, F. E.M. (2014). The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.

Palliative Medicine. 28, 9, 1081–1098.

DOI: 10.1177/0269216314531999

Patel, K., Janssen, D., J., Curtis, J. R. (2012). Advance care planning in COPD. *Respirology. 17*, 72-8.

doi.org/10.1111/j.1440-1843.2011.02087.x)

Philip, J., Gold, M., Brand, C., Miller, B., Douglass, J., Sundararajan, V. (2014). Facilitating Change and Adaptation: The Experiences of Current and Bereaved Carers of Patients with Severe Chronic Obstructive Pulmonary Disease. *Journal of Palliative Medicine, 17, 4.*

DOI: 10.1089/jpm.2013.0339

Pinnock, H., Kendall, M., Murray, S. A., Worth, A., Levack, P., Porter, M., MacNee, W., Sheikh, A. (2011). Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ, 342.*

doi.org/10.1136/bmj.d142

The Princess Royal Trust (2010). Evaluation of the Care-Plus Project – an Integrated Support Package. Year 3 Final Report. www.arup.com Job number 126196-00

Puhan. M.A., Garcia-Aymerich, J., Frey, M., et al. (2009). Expansion of the prognostic assessment of patients with chronic obstructive pulmonary disease: the updated BODE index and the ADO index. *Lancet,* 374: 704–711

Reilly, C.C. (2015). Patients' experiences of a new integrated breathlessness support service for patients with refractory breathlessness: Results of a postal survey. *Palliative Medicine, 1–10.*

DOI: 10.1177/0269216315600103

Reinke, L. F., Slatore, C. G., Uman, J., Udris, E. M., Moss, B. R., Engelberg, R. A. (2011). Patient-clinician communication about end-of-life care topics: Is anyone talking to patients with chronic obstructive pulmonary disease? *J Palliat Med,*

14, 8, 923–928.

Reticker. A., Nici, L., Zu Wallack, R. (2012). Pulmonary rehabilitation and palliative care in COPD: Two sides of the same coin? *Chronic Respiratory Disease, 9,* 2, 107-116

doi:10.1177/1479972312441379

Rocker, G., Young, J., Donahue, M., Farquhar, M., Simpson, A. C. (2012). Perspectives of patients, family caregivers, and physicians about the use of opioids for refractory dyspnoea in advanced chronic obstructive pulmonary disease. *Canadian Medical Association Journal. 184,* 9.

DOI:101503/cmaj111758.E497-E504.

Roberts, J. A., Maslin, T. K., Bakerly, N. D. (2010). Development of an integrated chronic obstructive pulmonary disease service model in an inner-city region in the UK: initial findings and 12-month results. *Prim Care Respir. 19, 4,* 390-7.

doi: 10.4104/pcrj.2010.00071

RCGP. (2011). The GSF Prognostic Indicator Guidance. The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life, *Royal College of General Practitioners*.

SCIE. (2013). Dying well at home: research evidence.

www.scie.org.uk

Scottish Government. (2010). Caring Together. The Carers Strategy for Scotland. T. S. Government. St Andrew's House

Edinburgh. EH1 3DG, The Scottish Government

http://www.gov.scot/Resource/Doc/319441/0102104.pdf

Seamark, D., Blake, S., Seamark, C., Hyland, M.E., Greaves, C., Pinnuck, M., Ward, D., Hawkins, A., Halpin, D.,& The East Devon Respiratory Research Group. (2012). Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study. *Prim Care Respir, 21,3,* 261-266.

Seymour, J., Almack, K., & Kennedy, S. (2010). Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative* Care, *9.* 4.

doi:10.1186/1472-684X-9-4

Simpson, A.C., Young, J., Donahue, M., & Rocker, G. (2010). A day at a time: caregiving on the edge in advanced COPD. *Int J Chron Obstruct Pulmon Dis. 2010, 5,* 141–151.

Simpson, C. (2012). Advance care planning in COPD: Care versus ''code status''. *Chronic Respiratory Disease, 9, 3,* 193–204.

DOI: 10.1177/1479972312445897

Smith, S. M. S., Sonego, S., Ketcheson, L., Larson, J. L. http://bmjopenrespres.bmj.com/content/1/1/e000042.short - aff-3 (2014). A review of the effectiveness of psychological interventions used for anxiety and depression in chronic obstructive pulmonary disease. *BMJ Open Resp Res, 2014, 1,* e000042

doi:10.1136/bmjresp-2014-000042

Sunde, S., Aksel, R., Walstad, S., Bentsen, B., Lunde, S. J., Wangen, E. M., Rustøen, T., Henriksen, A.H. (2014). The development of an integrated care model for patients with severe or very severe chronic obstructive pulmonary disease (COPD): the COPD–Home model. *Scand J Caring Sci, 28,* 469–477.

The Health Foundation (2010). Evidence Scan: Complex adaptive systems.

Titova, E., Steinshamn, S., Indredavik, B., & Henriksen, A.H. (2015). Long term effects of an integrated care intervention on hospital utilization in patients with severe COPD: a single centre controlled study. *Respiratory Research, 16,8.*

DOI 10.1186/s12931-015-0170-1

Trivedi, R. B., Bryson, C. L., Udris, E., & Au, D. H. (2012). The Influence of Informal Caregivers on Adherence in COPD Patients. *Ann. Behav. Med. 44,* 66–72.

DOI 10.1007/s12160-012-9355-8

Ventura, A. D., Burney, S., Brooker, J., Fletcher J., & Ricciardelli, L. (2014). Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers. *Palliative Medicine. 28, 5,* 391–402.

DOI: 10.1177/0269216313511141

Vitacca, M., Grassi, M., Barbano, L., Galavotti, G., Sturani, C., Vianello, A., Zanotti, E., Ballerin, L., Potena, A., Scala, R., Peratoner, A., Ceriana, P., Di Buono, L., Clini, E., Ambrosino, N., Hill, N., Nava, S. (2010). Last 3 months of life in home-ventilated patients: the family perception. *Eur Respir J.* 35, 5:1064-71.

DOI: 10.1183/09031936.00061009

Wagner, Austin and Von Korff (1996). Organizing Care for Patients with Chronic Illness. *The Milbank Quarterly,* 74, 4, 511-544

10.2307/3350391

Ward, S., Donnelly, C., Cooper-Taylor, CD., & Cooper-Taylor, P. (2014). Don’t forget to breath. A guide for COPD patients and their carers.

DontForgetToBreathe.org.nz

Westwood, D. K., & Bagshaw, K., Curtis et al. (2012). "Audit of the Use of ‘Just-In-Case’ Boxes as Part of a Local Enhanced Service Agreement for End of Life Care." *BMJ Supportive & Palliative Care, 2, (Supp 1),* A1- A120.

White, P., White, A., Seed, P., Edmonds, P., Gysels, M., Moxham, J., Shipman, C. (2011). Palliative care or end-of-life care in advanced chronic obstructive pulmonary disease. A prospective community survey. *Br J GenPract.* 61, 587:e362-70.

DOI: 10.3399/bjgp11X578043

Wood, N., & Drummond, B. (2013). Boost: A free 6 week course for improving mental wellbeing for the public. Report of the delivery and development of the Boost course in Manchester 2012-2013. *Manchester Mental Health and Social Care NHS Trust.*

Young, J., Donahue, M., Farquhar, M., Simpson, A. C., Rocker, G. (2012a).   Attitudes to Using Opioids to Treat Dyspnoea in Advanced COPD: A Qualitative Study of Family Physicians and Respiratory Therapists. *Canadian Family Physician. 58,* e401-7.

Young, J., Simpson, A.C., Demmons, J., Conrad, W., Rocker, G. (2012b).   Evaluating the impacts of "INSPIRED:" A new outreach program for patients and families living with advanced chronic obstructive pulmonary disease (COPD).   *Am J Respir Crit Care Med, 85,* A3732.

Zakrisson, A. B., Theander, K., Anderzén-Carlsson, A. (2013). The experience of a multidisciplinary programme of pulmonary rehabilitation in primary health care from the next of kin’s perspective: a qualitative study.   *Prim Care Respir J, 22,* 459-465