



Ready for Home?

Improving hospital discharge care for people living with COPD

A report by the British Lung Foundation and the
British Thoracic Society



British Lung Foundation

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Foreword

The British Lung Foundation (BLF) and the British Thoracic Society (BTS) are pleased to present this report. It is the product of two surveys conducted in 2009-10 through hospitals in the UK and with patients about how well organisations and people are prepared for being discharged from hospital with COPD.

The picture is one that shows from both sides there is room for improvement and the BLF and BTS are agreed in their determination to help to remedy this situation. Work will now commence on providing a checklist for hospital staff to use when discharging a patient and for patients in ensuring that when being discharged they know what to ask hospital staff and how to prepare themselves for going home.

This is an important issue as emergency admissions for COPD are the second highest of any disease area in the UK, resulting in excess of 1 million bed days. One in three people are being readmitted within 28 days.

This work will, we hope, help to take forward a difficult issue.



Professor Mike Morgan
Chairman
British Thoracic Society



Dame Helena Shovelton
Chief Executive
British Lung Foundation

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1 Introduction and overview

What is COPD?

Chronic obstructive pulmonary disease (COPD) is an umbrella term for a group of lung diseases which include chronic bronchitis and emphysema.¹ COPD is a preventable, progressive and life-limiting disease, which, as the UK's 5th biggest killer, claims more lives than breast, bowel or prostate cancer.¹ Approximately 900,000 people have been diagnosed with COPD in the UK, but it is estimated that the true number of people living with the disease could be as high as 3.7 million.¹

COPD is characterised by a long-term cough, breathlessness and wheeze, and the production of sputum (phlegm).¹ These symptoms can affect the quality of life for people living with COPD – their families and carers are also affected as normal, day-to-day activities are limited or stopped altogether.

Introduction

People living with COPD are also at risk of experiencing a flare-up (also known as an exacerbation). Flare-ups are defined as episodes of acute and sustained worsening of a person's day-to-day symptoms.² They can be extremely distressing and frightening, and are also associated with a worse quality of life, faster disease progression and increased mortality. Flare-ups are also a significant cause of hospital admission, readmission, and substantial healthcare costs.² Of considerable concern, recent data published by the office for UK National Statistics show that the rate of readmission following hospitalisation for a flare-up is increasing, with one in three people with COPD now being readmitted within 28 days of discharge.²

Given this background, the British Lung Foundation (BLF) and the British Thoracic Society (BTS) recently conducted two surveys to obtain information about the care provided to people with COPD when discharged from UK hospitals following a flare-up of COPD. The aim of the surveys was to improve strategies to prevent unnecessary readmissions.

The BLF survey, called 'Ready for Home?', asked people with COPD about their experiences of hospitalisation for a flare-up, particularly the support they received at the critical time of going home from hospital. The BTS survey, called 'Heading Home to Stay

Home', asked healthcare professionals involved in the discharge of COPD patients about their hospital's procedures, including the advice given to patients at discharge.

Summary of results

The 'Ready for Home?' survey showed that the majority of people with COPD:

- did not feel ready to go home when discharged from hospital
- felt poorly prepared for the future management of their COPD
- had not changed the way they managed their condition following hospitalisation
- would like more information and support when discharged from hospital
- were unaware that they were having an flare-up when admitted to hospital

In addition, a worrying number of people had delayed seeking medical help despite characteristic symptoms of a flare-up, with many being admitted to hospital as a result of going to accident and emergency or calling for an ambulance.

Summary of results

The 'Heading Home to Stay Home' survey showed that:

- many patients are not seen by a specialist before discharge
- many patients are not given appropriate post-discharge advice or follow-up arrangements
- only a third of hospitals use a formal discharge check list

Improving discharge care of people admitted to hospital for COPD flare-up

Whilst admissions for flare-ups of COPD are common, results of the surveys show that many hospitals in the UK do not provide sufficient quality of care or prepare patients adequately for discharge.

The BLF and BTS are currently developing a COPD discharge check list to assist hospitals in improving their discharge procedures, thus ensuring that people and carers feel more 'secure' when returning home after a flare-up of COPD. The check list will focus on activities that:

- improve the support given to COPD patients and carers when discharged
- improve COPD patients' and carers' understanding of flare-ups
- improve consistency of care across all hospitals

Work will begin in January 2011 and regular progress reports will be made throughout the year.



2 About COPD flare-ups (exacerbations)

Signs and symptoms of a flare-up

A flare-up (or exacerbation) of COPD is defined as a sustained worsening of an individual's symptoms from their usual stable state, which is rapid in onset. Commonly reported symptoms are worsening breathlessness, cough, and increased sputum production and change in sputum colour.² Worsening of these symptoms often necessitates a change in treatment which can be managed within the home, but more severe cases may require admission to hospital.

Impact of flare-ups

COPD flare-ups are associated with worse quality of life, faster disease progression and increased mortality. They are also a significant and increasing cause of hospital admission, readmission, and considerable healthcare costs.²

- Patients who have frequent flare-ups have a worse quality of life than those with infrequent flare-ups, and are more likely to become housebound³
- Flare-ups are frightening and distressing for people with COPD; they often say it feels like they are drowning or suffocating because breathing becomes so difficult⁴
- On average, 15 % of those admitted to hospital die within three months, and around 25 % die within a year of admission²
- Between 1991 and 2001, age-adjusted rates of admission for COPD rose by 50 %²
- 2008 data show that 33 % of people discharged from a UK hospital following a flare-up are likely to be readmitted within 28 days (mean time of readmission of 38 days); up from 31 % in 2003²
- Hospital admissions represent a significant part of the direct cost of COPD to the UK healthcare system, the total cost of which is currently estimated to be between £810 million and £930 million a year²
- COPD is the second most common cause of emergency admission to hospital,² and the fifth largest cause of readmission to hospital²
- Hospital data clearly show that the majority of admissions for COPD are unscheduled and, as such, present a high burden of cost to the NHS²

Guidance and policies on the discharge of patients admitted with flare-ups

a) Strategy for Services for COPD in England

The NHS and Department of Health (DoH) are soon to introduce a Strategy for Services for COPD in England to improve the care and outcome for those with COPD, and to curtail the large and increasing healthcare costs of COPD, particularly those associated with acute hospital care.² This strategy is in line with, and expands upon, the 2010 National Institute of Clinical Excellence guidelines for the management of COPD.⁵

Regarding the management of those admitted for a flare-up of COPD, the draft strategy makes the following recommendation:

“People with COPD should receive a specialist respiratory review when acute episodes have required referral to hospital. They should be assessed for management by early discharge schemes, or by a structured hospital admission, to ensure that length of stay and subsequent readmission are minimised.”

Information surrounding this recommendation is as follows:

- **Key elements of patient review/assessment**
Review and assessment of patients hospitalised for a flare-up of COPD should involve:²
 - Treatment regimens
 - Co-morbid conditions
 - Need for other investigations
 - Psychosocial needs
 - Adherence and concordance with current medications and other interventions
 - Need for post-flare-up pulmonary rehabilitation
 - Need for ongoing community-based support (e.g. oxygen therapy, nasal intervention)
- **Importance of review by COPD specialists**
Patients admitted to hospital should be reviewed and assessment should be made by medical teams with experience in the management of respiratory failure in COPD, as evidence from a UK audit shows that outcome is improved in hospitals where specialist respiratory physicians are present.²
- **Hospitalisation provides an opportunity for patient education**
Hospitalisation should be taken as an opportunity to provide patients (and carers) with information and advice about their condition, including:²

- COPD
 - Recognising the symptoms of a flare-up – evidence shows that early treatment from the outset of symptoms improves outcome
 - Who they should contact in the event of a future attack
 - Management of breathlessness
 - Smoking cessation (if required)
- **Effective discharge procedures**
Effective discharge involves good communication between hospitals and community-based professionals involved in the care of those with COPD, such as general practitioners and social care workers. Hospitals should ensure that any required community-based care and support is in place before the patient is discharged, and that the patient's notes and discharge summary are promptly provided to all relevant personnel.²
 - **Early supported discharge (ESD)**
Early supported discharge from hospital is recognised as an important component of care for some people admitted with flare-ups of COPD. The aim is to facilitate the early discharge of patients admitted with flare-ups by providing increased medical, nursing, and social support in the community. Early supported discharge following review and assessment of the patient by specialist healthcare professionals has been shown to be as effective as similar integrated care services in reducing the rates of readmission.

Early supported discharge (ESD) is one of three other key types of integrated care service used in chronic disease management:

1. Admission avoidance following Accident & Emergency attendance
2. Admission avoidance following direct GP referral
3. Combination of admission avoidance and ESD

Early supported discharge is preferred by people with COPD and is less costly than usual care.²

The principles of early supported discharge outlined in the draft Strategy for Services for COPD in England concur with the general DoH guidelines for the planning, discharge and transfer of patients from hospital (Ready to Go?), which were published in March 2010 (Table 1).⁶ A shorter hospital stay reduces the risk of infection and inappropriate use of NHS resources, as well as reducing patients' depression/low mood, boredom, frustration, loss of independence and confidence. However, premature discharge can leave the patient and carer with some unmet needs, poorly prepared for home, at increased risk of readmission, or using inappropriate or more costly social care services.

Table 1 DoH recommendations for the effective discharge of patients from hospital⁶

1.	Start planning for discharge or transfer before or on admission
2.	Identify whether patient has simple or complex discharge and transfer planning needs, involving the patient and carer in your decision
3.	Develop a clinical management plan for every patient within 24 hours of admission
4.	Co-ordinate the discharge or transfer of care through effective leadership and handover of responsibilities at ward level
5.	Set an expected date of discharge or transfer within 24-48 hours of admission, and discuss with the patient or carer
6.	Review the clinical management plan each day, take any necessary action and update progress towards the discharge or transfer date
7.	Involve the patient and carers so that they can make informed decisions and choices that deliver a personalised care pathway and maximise their independence
8.	Plan the discharges and transfers to take place over seven days to deliver continuity of care for the patient
9.	Use a discharge check list 24-48 hours prior to transfer
10.	Make decisions to discharge and transfer the patients each day

b) The 30-day readmission policy for England

Changes in the way that hospitals in England are reimbursed for treatment should have a positive impact on the care provided to people with COPD when discharged from hospital after a flare-up.

From 1 December 2010, hospitals are to become responsible for patients for the 30 days after discharge. If a patient is readmitted within this time, the hospital will not receive any further payment for the additional treatment.⁷

The aim of the 30-day readmission policy is to encourage hospitals to work more closely with GPs and other community-based health and social care agencies before discharging patients. It is hoped that providing a more seamless service after discharge from hospital will contribute to improved patient outcomes and significantly reduce the risk of emergency readmission into hospital, which increased by 50 % between 1989/99 and 2007/08.

“Too often patients end up back in hospital because they haven’t had help readjusting to life at home. We need to do more to prevent this from happening.”

Andrew Lansley, Health Secretary, 24th October 2010⁸

3 The 'Ready for Home?' survey of people with COPD

Background

'Ready for Home?' was a survey organised by the BLF aimed at understanding the needs and experiences of people with COPD who had been admitted to hospital for a flare-up of their condition. The purpose of the survey was to improve patient support services, especially at the critical time of going home from hospital.

Information was collected anonymously, using a self-administered questionnaire that contained five questions about the person's COPD, six questions about events leading to their last hospitalisation for COPD, 15 questions about being discharged home, and seven questions about ways in which support services could be improved.

The survey was conducted between November 2009 and February 2010, and a total of 307 people with COPD were recruited through Breathe Easy support groups, the BLF website and a market research panel. 83% of those in the survey were aged 56 years or older, 89% had established COPD (diagnosed more than 12 months ago), and 39% had been admitted to hospital for COPD within the last 12 months.

Survey findings

a) How people felt when discharged from hospital

When asked how they felt when being discharged from hospital following treatment for COPD, only about a quarter to one third of respondents said they were 'very' confident about going back home or about the future management of their condition (Table 2). Key findings were:

- Only 25 % felt ready to leave hospital
- Only 26 % felt able to cope at home
- Only 37 % felt reassured that good support was available at home
- Only 34 % felt informed about their COPD and reasons for admission

- Only 31 % felt confident that COPD medication could help
- Only 34 % felt confident about spotting early signs of their condition worsening
- Only 24 % felt positive about the future

However, 60 % of people with COPD felt ‘very’ confident about how/when to take their medications.

Most people with COPD felt apprehensive about going back home and poorly prepared for the future management of their condition

Table 2 How people feel when discharged from hospital following treatment for COPD*

	Very	Fairly	Neither yes or no	Not really	Not at all	Don't know
Ready (well enough) to leave hospital	25 %	47 %	7 %	10 %	2 %	9 %
Reassured about being able to cope at home	26 %	43 %	8 %	12 %	3 %	8 %
Informed about your COPD and reasons for admission	34 %	28 %	11 %	10 %	6 %	11 %
Confident about how/when to take medications	60 %	24 %	4 %	2 %	2 %	8 %
Confident that COPD medications could help	31 %	48 %	8 %	5 %	1 %	8 %
Confident about spotting early signs of worsening	34 %	45 %	6 %	6 %	2 %	7 %
Reassured that good support was available at home	37 %	28 %	9 %	12 %	7 %	8 %
Positive about the future	24 %	35 %	16 %	13 %	5 %	7 %

* Not all the 307 survey participants answered every question.

b) Effect of hospitalisation on how people managed their COPD

When asked whether their last hospitalisation for COPD had changed the way they managed their condition, relatively few people said it had had a positive effect (Table 3). Key findings were:

- Only 29 % had increased their level of activities and general exercise (17 % said it had decreased)
- Only 40 % felt better able to arrange their life to cope with COPD (12 % felt less able)
- Only 42 % said they were better at taking their medications on time as prescribed
- Only 54 % considered their knowledge of when to seek help about feeling unwell had increased
- Only 35 % had made greater effort to give up smoking/avoid smoking

- Only 27 % had participated in discussion forums/groups more often (8 % less often)
- Only 27 % had used available community support services more often (7 % less often)

Most people with COPD said hospitalisation had not changed the way they managed their condition

Table 3 Effect of hospitalisation on how people managed their COPD

	Increased/ better/ more often	Reduced/ worsened/ less often	No change
Level of exercise and general activities	29 %	17 %	54 %
Ability to arrange your life to cope with COPD	40 %	12 %	48 %
Taking your medications on time as prescribed	42 %	1 %	57 %
Knowing when to seek help about feeling unwell	54 %	3 %	43 %
Efforts to give up/avoid smoking	35 %	3 %	62 %
Participation in discussion forums/groups	27 %	8 %	66 %
Use of available community support services	27 %	7 %	66 %

* Not all the 307 survey participants answered every question.

c) The type of support people with COPD would like when discharged from hospital

When questioned about ways in which the discharge procedure from hospital could be improved, most people said they would like more information and support to help them manage their COPD, including:

- More information on the reasons for admission (75 %), treatment choices (80 %), COPD patient organisations (68 %), and healthcare professional support available at home (78 %)
- More contact from healthcare professional support services (75 %)
- Practical advice about lifestyle/social/other coping issues (69 %)
- Practical advice and support via a telephone helpline (64 %)

Presently, patients and carers are looking for more advice and help throughout all stages of their treatment pathway:

“Generally [I would] just [like] someone to talk to”

“There seems to be little advice or help unless one pesters the GP”

“[I would like] regular visits from a respiratory nurse”

“[I] think hospitals should listen more and not send you home too early”

d) Events leading to hospitalisation

Answers relating to events that had led to people's last hospitalisation for COPD treatment showed that a worrying number had delayed seeking medical help, despite characteristic symptoms of COPD. Many people had been admitted to hospital as a result of going to accident and emergency, or as a result of them, or someone else, calling an ambulance. In addition, more than half of people with COPD were unaware that they had been admitted for treatment of a flare-up.

- 80 % of patients had experienced the onset/worsening of shortness of breath, and/or other characteristic signs of a flare-up
- 56 % had felt unwell/more unwell than usual for 24 hours or more before being admitted
- 41 % had been admitted as a result of going to accident and emergency (11 %) or because they or someone else had called an ambulance (30 %)
- 26 % believed that their delay in seeking medical help had contributed to the need for hospitalisation
- Only 46 % said they were aware that they had been admitted for treatment of a flare-up

Many people with COPD had delayed seeking medical help for symptoms or problems and most were unaware of the reason for being hospitalised

4 The 'Heading Home to Stay Home' survey of hospital discharge procedures



Background

'Heading Home to Stay Home' was a national survey organised by the BTS aimed at obtaining a better picture of the advice given to COPD patients when discharged from hospital. The purpose of the survey was to improve strategies to prevent unnecessary readmissions.

A questionnaire, developed by the respiratory medical department at Glenfield Hospital, Leicester, was sent to respiratory departments in all acute hospitals in the United Kingdom. Healthcare professionals involved in the discharge of COPD patients were asked for background details about their hospital, and then to answer eight questions about their hospital's processes and the provision of information to patients at discharge.

The survey was conducted between February and March 2010, and healthcare professionals from 68 hospitals returned the questionnaire. The hospitals covered all regions of England,

as well as Scotland and Wales, and the majority (69%) were district general hospitals (DGHs) rather than teaching hospitals. The catchment population of the participating hospitals ranges from 100,000 to 1 million, and the respiratory departments vary in size from fewer than 20 beds (10.3%) to more than 60 beds (11.8%). Almost half the hospitals (49%) have more than 70 COPD admissions per month, and the majority of both DGHs (64%) and teaching hospitals (86%) have an early discharge service. In most cases the early discharge service is based in the hospital (70% for DGHs and 61% for teaching hospitals) rather than the community.

Survey findings

Current discharge procedures in UK hospitals

The survey results revealed that the care provided to many patients admitted to hospital for a flare-up is less than ideal (Table 4):

- Only 53 % of patients were seen by a respiratory physician before discharge; 69 % were seen by a specialist nurse
- Only 32 % of hospitals use a formal discharge check list
- Only 22 % of hospitals have a COPD discharge pack for patients
- 31 % of hospitals do not give patients a copy of the discharge letter
- Only 52 % of hospitals refer patients directly to pulmonary rehabilitation
- Only 63 % of hospitals refer patients to their smoking cessation service

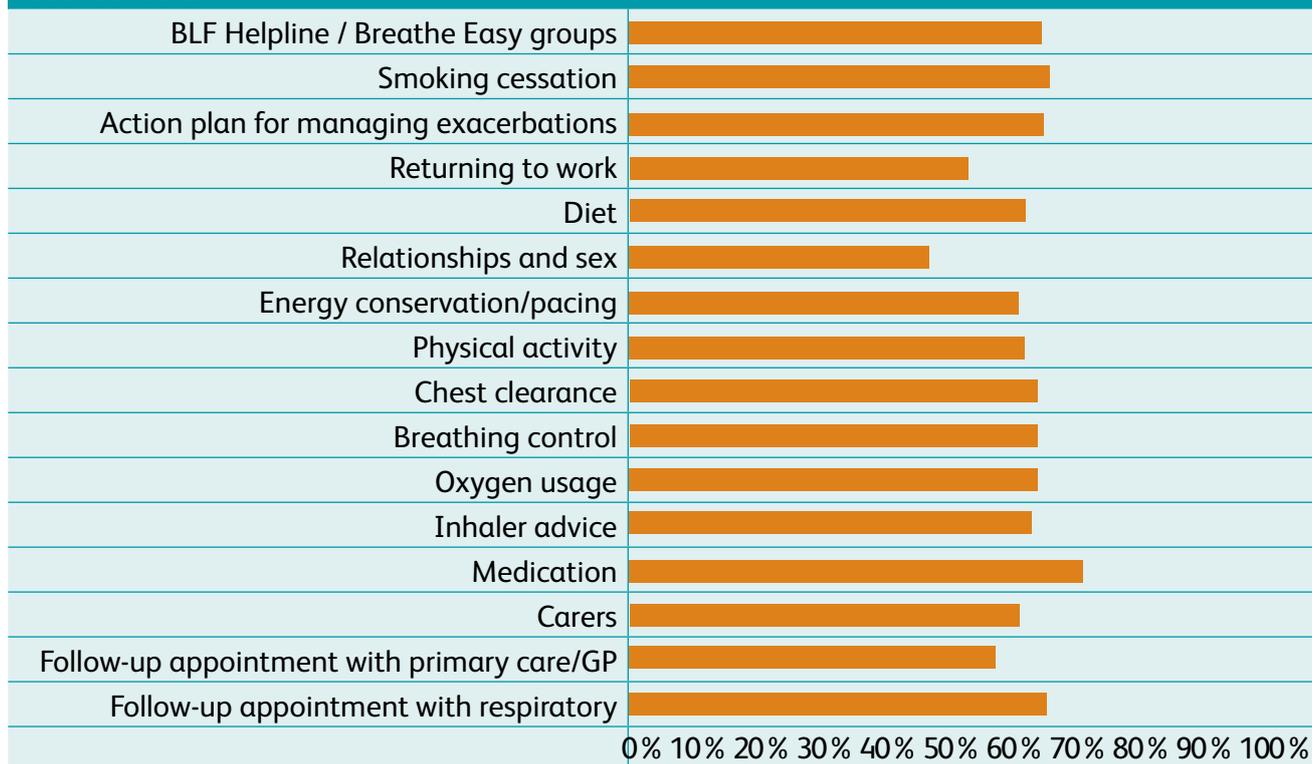
In addition, follow-up appointments within primary or secondary care were not universally arranged (59 % and 67 % respectively), and there was patchy coverage of educational advice to patients, especially regarding return to work or sexual relationships (Figure 1).

Table 4 Discharge care provided by UK hospitals

	District General Hospital	Teaching hospital	Overall*
Patient seen by a respiratory physician before discharge	51 %	57 %	53 %
Patient seen by a specialist nurse before discharge	68 %	71 %	69 %
Hospitals using a formal discharge check list	30 %	38 %	32 %
Hospitals with a discharge pack for COPD patients	19 %	29 %	22 %
Patients given copy of the discharge letter	66 %	76 %	69 %
Patients referred directly to pulmonary rehabilitation	55 %	53 %	52 %
Patients referred to hospital's smoking cessation service	68 %	53 %	63 %

* Overall percentages are based on all the results obtained in the survey. Since some respondents did not answer all questions asked, these percentages are slightly different than would be obtained by averaging the individual DGH and teaching hospital results.

Figure 1 Information/advice given to COPD patients during hospitalisation for an exacerbation



Many patients do not see a respiratory physician before discharge or have appropriate post-discharge advice or follow up arrangements

Healthcare professionals have identified challenges in the admission and discharge process:

“Diagnosis on admission is a problem – many patients are labelled as COPD who have not got this diagnosis and the other way round. There are also issues of capacity – if all patients would be identified correctly they could not be taken over by the respiratory team”

“[The discharge process] needs to be more secure. A discharge check list would be a good idea as patients are not always given follow up appointments or entirely the correct meds”



5 Improving discharge procedures

COPD flare-ups are associated with worse quality of life, faster disease progression and increased mortality. They are also a significant and increasing cause of hospital admission, readmission, and substantial healthcare costs.² Of considerable concern, recent data shows that the rate of readmission following hospitalisation for a flare-up is increasing, with one in three people now being readmitted to hospital within 28 days of discharge.²

Key factors in reducing readmission for COPD

Treatment guidelines for COPD emphasise that the likelihood of a patient being readmitted to hospital is influenced by the support they receive during hospitalisation, particularly at the critical point of going home. Key elements of effective support are:²

- Assessment and preparation for discharge should be under the direction of a specialist respiratory physician
- Hospitalisation should be taken as an opportunity to provide people with information about COPD, its management, and the various community services that are available to support them
- Hospitals should ensure that any required community-based care and support is in place before the patient is discharged

Preparation for discharge is inadequate in many hospitals

The results of the two surveys covered by this report show that many hospitals in the UK are not delivering these key elements of care for people admitted to hospital for a flare-up:

- Only half of patients were seen by a respiratory physician before discharge
- Only about a third of people discharged from hospital for COPD treatment said they felt informed about COPD, had been told their admission was for a flare-up of COPD, felt confident about spotting early signs of a future flare-ups, or had positively changed the way they managed their COPD
- Only a third of hospitals use a formal discharge check list and only a quarter have a discharge pack for COPD patients
- Post-discharge support was not universally given, including

referral to pulmonary rehabilitation or smoking cessation services, and booking of follow-up appointments within primary or secondary care

- Only a quarter to a third of people with COPD felt ready to leave hospital, reassured about being able to cope at home, or reassured that good post-discharge support was available

These findings will soon have financial consequences for hospitals in England. From December 2010, hospitals in England will not be reimbursed for the treatment of patients readmitted within 30 days of discharge, if it can be shown that they have not provided sufficient quality of care or prepared patients adequately for discharge.⁷

How the BLF and BTS will help improve discharge procedures

The BLF and BTS are currently developing a COPD discharge check list to assist hospitals in improving their discharge procedures, thus ensuring that patients and carers feel more 'secure' when returning home after a flare-up. The check list will focus on activities that:

- improve the support given to COPD patients and carers when discharged
- improve COPD patients' and carers' understanding of flare-ups
- improve consistency of care across all hospitals

Work will begin in January 2011 and regular progress reports will be made throughout the year.



About the British Lung Foundation

The British Lung Foundation (BLF) is the only UK charity working for everyone affected by any lung disease – whether it's mild asthma, COPD or lung cancer. We focus our resources on providing support and change for people affected by all aspects of lung disease.

- We help people to understand and manage their condition through our various support services, so they can cope with the individual challenges they face
- We work for positive change in lung health, by campaigning and raising awareness on all aspects of respiratory disease
- We fund world-class research to help improve diagnosis, treatment and care for the 8 million people with lung disease in the UK today and in the future

About the British Thoracic Society

The British Thoracic Society (BTS) is a registered charity and professional membership body. We have 2,800 members who are active throughout the United Kingdom (November 2010 figure). Our members include doctors, nurses, respiratory physiotherapists, scientists and other professionals with an interest in respiratory disease.

All join because they share an interest in our main charitable objective, which is to improve the care of people with respiratory and associated disorders. We do this by:-

- **promoting optimum standards of care** (for example Clinical Guidelines, Markers of Good Practice, Clinical Audit tools, which lie at the heart of what we do);
- **promoting and advancing knowledge** about the causes, prevention and treatment of respiratory diseases (the Society has an extensive range of educational activities, including e-learning modules, and its website provides valuable information to healthcare professionals and the general enquirer);
- **promoting and disseminating research** (the Society's journal Thorax is the second highest rated of its type in the world and the BTS Winter Meeting provides a platform for scientists and researchers as well as active respiratory clinicians to hear about developments in lung research and applications for the benefit of patients) .

We have a strong internal infrastructure to support our active members. In 2010 around 13 % of our members were active in a range of ways, for example serving on committees and advisory groups, providing input into activities such as guideline production and development of education materials, and representing the Society on external bodies and consultations. The BTS Public Liaison Committee is developing activities which will define what the public might expect from an excellent respiratory service and also looking into how people with respiratory conditions requiring treatment can make the most of their respiratory consultations, working in partnership with the respiratory team.

The Society is committed to working in partnership with a range of organisations to achieve our objectives. These include other respiratory health professional groups, organisations representing patients and carers, government departments, health services agencies, medical and surgical royal colleges, and other specialist societies.

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British Lung Foundation

British Lung Foundation

73-75 Goswell Road

London EC1V 7ER

Tel: 0207 688 5555

Helpline: 08458 50 50 20

E: enquiries@blf-uk.org

W: www.lunguk.org



British Thoracic Society

17 Doughty Street

London WC1N 2PL

Tel: 0207 831 8778

Fax: 0207 831 8766

E: bts@brit-thoracic.org.uk

W: www.brit-thoracic.org.uk