

Manifesto

March 2005



**One person in seven in the UK is affected by a lung disease.
The British Lung Foundation is the only UK charity working to help people
with all 43 lung diseases.**

**The British Lung Foundation provides information and support to patients
and their families, funds world class medical research to find solutions to
lung disease and campaigns for improved treatments and services.**

The British Lung Foundation calls on the next Government to:

- 1** Provide five specialist respiratory paediatricians in every specialist centre in the UK.
- 2** Ensure Pulmonary Rehabilitation is available to all lung disease patients who could benefit from it.
- 3** Provide ambulatory oxygen to all lung disease patients on long-term oxygen therapy.
- 4** Prepare and implement a treatment and care strategy for mesothelioma.
- 5** Provide palliative care to patients with end-stage chronic lung disease.
- 6** Increase the number of PET scanners in the NHS to ensure that all patients have quick and equal access to imaging facilities.
- 7** Introduce routine lung function tests at GP consultations for all patients with a smoking history.
- 8** Ban smoking in all enclosed public places and work places.

1 Provide five specialist respiratory paediatricians in every specialist centre in the UK.

Respiratory diseases are very common in babies and infants while their lungs are still developing. Not only do respiratory diseases cause serious illnesses and worry parents, they may cause damage to the lungs which is permanent and may be the main reason why many respiratory illnesses occur in adult life.

Over the last 20 years, the care of premature babies has improved greatly because of our increased understanding of the underlying problems. However, this has resulted in the survival of many more immature babies and it is now more likely that babies born at 24 weeks gestation will survive than those born 10 or 20 years ago. These babies are more prone to catching potentially fatal infections, such as respiratory syncytial virus (RSV) or pneumonia as well as other viral and bacterial infections.

- 34% of weekly GP consultations in children are due to respiratory illnesses¹
- 15% of hospital admissions in children are due to respiratory complaints²
- The prevalence of respiratory disease in children is greater than

that from all other chronic illnesses combined³

- Among respiratory illnesses, acute viral upper respiratory infections and asthma are the commonest with asthma being the most common chronic disease in children.

The majority of children admitted to hospital with respiratory problems are treated by general paediatric physicians as they are not admitted to a specialist tertiary care centre.

There are 64 specialist respiratory paediatricians in the UK, in 21 tertiary care centres, covering an estimated population of 2-2.5 million people each. Current estimates suggest there is a shortfall of 58 specialist respiratory paediatricians. Taking account of expected retirements, it is believed that an expansion of five full time equivalent posts a year is needed to correct the shortfall over the next 12 years⁴.

It is vital that these additional specialist respiratory paediatricians are employed in the NHS to provide the best possible care to children suffering from conditions such as RSV, bronchiolitis and recurrent wheeze.

The British Lung Foundation calls on the next Government to recruit additional specialist respiratory paediatric consultants to ensure five full time equivalent positions are provided in each tertiary care centre.

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2 Ensure Pulmonary Rehabilitation is available to all lung disease patients who could benefit from it.

Pulmonary rehabilitation, an exercise and lifestyle programme, is designed to help people with serious lung conditions, particularly Chronic Obstructive Pulmonary Disease (COPD), cope with breathlessness and feel stronger and fitter.

There are 900,000⁵ people living with COPD in the UK but it is estimated that 75 per cent of cases are not diagnosed⁶.

People with lung conditions often reduce the amount of activity they do because getting breathless can be frightening. However, this does not help as over time they will become unfit, tired and more breathless. Pulmonary rehabilitation is designed to break that cycle.

Trained health professionals teach patients how to increase their activity carefully, cope with breathlessness and manage their condition. Patients who have completed pulmonary rehabilitation benefit from greater exercise capacity and physical endurance, better emotional function, reduced breathlessness, improved self-esteem and improved independence.

Most programmes are between seven and 12 weeks in duration and consist of two sessions a week.

Research by the British Lung Foundation found that:

- 160 hospitals/chest clinics provide some sort of pulmonary rehabilitation
- 86 (57%) of these programmes receive secure funding
- 15 (10%) of these programmes receive no NHS funding
- 15% of programmes provide access to 100 patients or more per year
- One third of established programmes are unable to provide an adequate number of physical training sessions
- 55 (36%) of these programmes provide follow up care for patients once their pulmonary rehabilitation has been completed
- 67 (43%) of these programmes have a BLF Breathe Easy group either attached to the hospital or running within the immediate area for patients to attend.

The National Institute of Clinical Excellence (NICE) Clinical Guideline on the Management of COPD in Primary and Secondary Care recommends pulmonary rehabilitation as an effective therapy which should be provided.

The British Lung Foundation calls on the next Government to provide secure funding to ensure that pulmonary rehabilitation is available to all patients who could benefit from it.

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3 Provide ambulatory oxygen to all lung disease patients on long-term oxygen therapy.

Oxygen therapy and its use in the home environment has developed over the past 50 years with the introduction in 1985 of the domiciliary oxygen concentrator service for people on long-term oxygen therapy. Prior to this oxygen had only been available in cylinder form. Since 1985 the number of people being prescribed with oxygen in the UK has increased to 70,000⁷.

Lung disease is highly disabling, particularly for patients on long-term oxygen therapy. Many patients are hooked up to large cylinders for more than 20 hours a day and are only able to move as far as their plastic tubing will allow – this is often not even as far as upstairs in their own house. As a result many patients become housebound and feel increasingly isolated.

Ambulatory light-weight cylinders are portable and therefore allow patients to leave their homes, to visit friends and relatives, to do the shopping, or to simply get some fresh air. This is one of the most beneficial ways of improving the lives of people who need oxygen. It is vital that this form of oxygen delivery

is made universally available on the NHS to ensure lung disease patients are able to maintain a good quality of life.

Liquid oxygen, which is widely available in the USA and many countries in Europe, is not freely available in the UK. For many patients this form of ambulatory oxygen would be ideal for their needs as it is much lighter to carry and lasts on average twice as long as portable gas cylinder oxygen.

The need for ambulatory and liquid oxygen is particularly important in paediatrics. As oxygen dependant infants become mobile and progress from toddlers to attending nursery and later school, the availability of light-weight cylinders and liquid oxygen is essential to allow normal mobility, development and education.

The Department of Health is currently undertaking a review of oxygen provision. It is imperative that this review is completed quickly and equality of provision is ensured to allow patients to benefit from ambulatory oxygen as soon as possible.

The British Lung Foundation calls on the next Government to ensure all lung disease patients on long-term oxygen therapy have access to light-weight portable (including liquid) oxygen cylinders.

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4 Prepare and implement a treatment and care strategy for mesothelioma.

A mesothelioma is a malignant tumour that arises within the mesothelium, a thin membrane that lines the chest (pleura) and the abdomen (peritoneum) and surrounds the lung or the bowel respectively. The pleural mesothelioma is much more common, and its rising incidence is causing concern.

A history of occupational exposure to asbestos can be found in about 90 per cent of mesothelioma cases⁸. The other causes of the disease are not fully understood. Neither smoking nor exposure to more modern fire resistant materials are thought to increase the risk.

Changes in the pleura occur when asbestos fibres are breathed in. Mesothelioma of the abdominal lining may result from inhaled asbestos fibres being coughed up and swallowed.

Family members of people exposed to asbestos also run a higher risk of developing mesothelioma. This is because workers can carry asbestos fibres home on their clothes⁹ and children living near to the asbestos works often played with the dust as if it were snow.

Mesothelioma is one of several types of chest disease which results from exposure to asbestos. It can develop more than 40 years after exposure with asbestos and because of this delay it has been calculated that the number of UK cases will continue to rise until 2015.

- There were 1,848 mesothelioma deaths in Great Britain in 2001¹⁰
- The total number of mesothelioma deaths in Great Britain is expected to peak at around 1,950-2,450 deaths sometime between 2011 and 2015¹¹
- Someone dies every five hours from mesothelioma in the UK¹²
- There are 33% more deaths from mesothelioma than from cervical cancer¹³
- Deaths from mesothelioma have increased 10-fold since 1968 in the UK¹⁴
- There will be more than a million deaths from mesothelioma in western Europe by 2035¹⁵
- The greatest risk group are men born between 1945 and 1950¹⁶

The British Lung Foundation calls on the next Government to prepare and implement a comprehensive treatment and care strategy for mesothelioma to ensure that patients receive the most effective and appropriate treatment possible.

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5 Provide palliative care to patients with end-stage chronic lung disease.

Patients with chronic lung disease can be extremely disabled and live lives which are greatly restricted by their condition. Patients often reduce the amount of activity they do because getting breathless can be very frightening. However, this does not help as over time they will become unfit, tired and more breathless. This vicious circle of disability ultimately results in patients becoming house bound (in some cases room bound) and increasingly isolated.

There is very limited support for these patients in terms of community based healthcare support and as far as we can ascertain there is no provision of palliative care at home for patients with severe chronic lung disease except for lung cancer and mesothelioma.

Serious lung diseases, such as chronic obstructive pulmonary disease (COPD), which are equally debilitating are not provided for in this regard, although patients may suffer for up to 10 years in a state of extreme distress.

This lack of support in the community leads to otherwise avoidable emergency hospital admissions and lengthier stays in hospital. The National COPD Audit found that more than one in 10 patients with COPD admitted to hospital is dead within 90 days of admission, and more than one in three is readmitted to hospital during that time¹⁷.

Geographically there is considerable variation in services offered by different councils. This is due to a mixed picture across the UK on the provision of specialist respiratory nurses. Provision of community-based care depends entirely on whether a respiratory nurse makes home visits in the patient's area – effectively resulting in a postcode lottery.

Patients with respiratory conditions are not entitled to hospice care. One COPD patient and member of one of the British Lung Foundation's Breathe Easy support groups explained that he considered himself lucky to have been additionally diagnosed with lung cancer as this afforded him access to hospice care.

The British Lung Foundation calls on the next Government to provide palliative care to all patients with end-stage chronic lung disease.

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6

Increase the number of PET scanners available to the NHS.

Positron Emission Tomography (PET) medical imaging scanners are considered to be the best method of diagnosing disease and evaluating the success of treatment for many different diseases, particularly for cancer. They can pick up possible disease earlier than other methods of scanning such as CT scan or MRI scan, and this allows doctors to target treatments better and monitor their progress.

There are over 160 PET sites in the USA and over 120 sites in Europe (80 in Germany, 14 in Belgium)

There are five scanners, used for routine clinical assessments, in the NHS and all are situated in London (Guys and St Thomas', Middlesex, Mount Vernon, Hammersmith). An additional four scanners have been set up for research.

PET can pick up disease changes (e.g. cancer activity) earlier than when such changes can be visualised by more conventional scanning techniques, such as CT or MRI. In these situations PET is more accurate than CT or MRI. For lung cancer, in particular, early diagnosis is vital for a patient to have any chance of survival.

The British Lung Foundation calls on the next Government to increase the number of PET scanners available for routine use in the NHS and ensure that all patients across the UK have quick and equal access to imaging facilities.

PET has already been shown to be cost effective in two specific areas for lung cancer¹⁸:

- Assessing whether lung tumours are benign or malignant. (PET is therefore invaluable for those lung cancer patients where conventional testing has not been able to differentiate and the biopsy is inconclusive)
- The staging of lung cancer, to assess whether or not the cancer is suitable for surgery.

In one study, 62 out of 102 patients with lung cancer being assessed for major surgery had their management changed after having a PET scan.¹⁹

The UK has fallen behind the rest of Europe and the US in the provision of PET.^{20,21}

According to the Intercollegiate Standing Committee for Nuclear Medicine "state of the art dedicated PET camera facilities should be established in at least 15 sites within the UK in the next three to five years, and in at least 40-60 sites in the next 10 years."

7 Introduce routine lung function tests for all patients with a smoking history.

GPs and primary care practitioners are in a unique position to improve early diagnosis for chronic lung diseases and lung cancer.

At every consultation with a patient who is a current smoker, or has a smoking history, a lung function or spirometry test should be conducted, in the same way that blood pressure is taken.

These tests can detect changes in lung function indicative of conditions such as chronic obstructive pulmonary disease (COPD) and lung cancer, conditions

where early diagnosis can greatly improve the prognosis for the patient.

In addition to this, spirometry testing can help to differentiate between asthma and COPD and can be hugely valuable in ensuring patients receive the most appropriate treatment for their condition.

The British Lung Foundation also calls on all politicians to encourage all current and former smokers, and people who have been exposed to secondhand tobacco smoke, to request lung function testing where it is not routinely offered.

The British Lung Foundation calls on the next Government to ensure routine lung function tests are conducted on all patients with a smoking history, regardless of the reason they have presented themselves at the surgery.

8

Ban smoking in all enclosed public places and work places.

Approximately one in five non-smokers in the UK is exposed 'frequently or continuously' to secondhand smoke at work²². Professor Jamrozik, formerly of Imperial College London, estimated that exposure to secondhand smoke at work leads to around 700 deaths from lung cancer, heart disease and stroke combined, he also estimates 49 deaths - or about one a week - from exposure at work in the hospitality trades.

The damage to lungs from secondhand smoke has long been acknowledged making this an important issue for both public health and health and safety at work. People should have the right to socialise and work in smoke-free environments without damaging their health. Lung conditions are seriously aggravated by exposure to secondhand smoke and patients are simply unable to breathe in smoky environments.

Air conditioning and filtering does not provide the complete protection needed. Filtration of indoor air to remove secondhand smoke contaminants is futile - like trying to filter a lake to control water pollution²³.

Separating smokers from non-smokers in the same space or on the same ventilation system exposes non-smokers to unacceptable risk²⁴.

It is our fear that proposals which allow smoking to continue in pubs and bars which do not serve food will only serve to increase the health inequalities gap. Initial data from research currently being conducted suggests that the majority of these so-called 'wet pubs' are situated in the most deprived wards in the country, where smoking prevalence, and therefore the rate of smoking related disease, is significantly higher.

Comprehensive national legislation prohibiting smoking in all public places and work places, such as that which has been successfully introduced in Ireland, Norway, and most recently, Italy, is the only way to ensure the health of workers is protected.

Evidence from these countries indicates that there has been no adverse effect on the hospitality or tourism industries and as a result quit attempts have increased and cigarette consumption and smoking prevalence have decreased. A survey by the national Quitline service in Ireland revealed that around 10,000 smokers report that they have reduced their consumption since the ban and according to the Irish Revenue Commissioners, sales of cigarettes fell almost 16% in the first six months of 2004²⁵.

The British Lung Foundation calls on the next Government to introduce legislation for a comprehensive ban on smoking in all enclosed public places and work places in the first Queen's Speech of the next Parliament.

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For further information, please contact:

**Donna Castle
Parliamentary Officer**

**British Lung Foundation
73-75 Goswell Road
LONDON
EC1V 7ER**

Switchboard: 020 7688 5555

Direct Line: 020 7688 5563

Fax: 020 7688 5556

Email: donna.castle@blf-uk.org

Website: www.lunguk.org

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⁶ Breathing Fear – The COPD Effect, British Lung Foundation 2003

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⁹ <http://www.cancerresearch.org.uk/aboutcancer/specificcancers/mesothelioma>

¹⁰ Written answer to parliamentary question from Desmond Browne MP to Simon Hughes MP 08-01-04

¹¹ Written answer to parliamentary question from Jane Kennedy MP to Huw Irranca-Davies MP 23-04-04

¹² <http://www.leeds.ac.uk/meso/meso.htm>

¹³ <http://www.leeds.ac.uk/meso/meso.htm>

¹⁴ <http://www.leeds.ac.uk/meso/meso.htm>

¹⁵ <http://www.leeds.ac.uk/meso/meso.htm>

¹⁶ <http://www.leeds.ac.uk/meso/meso.htm>

¹⁷ Report of the 2003 National COPD Audit compiled by the British Thoracic Society and the Royal College of Physicians (September 2004)

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