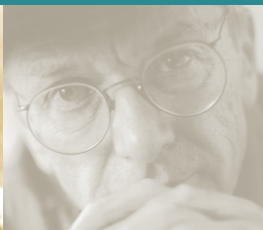


European COPD Patient Manifesto A Vision for Change



European Network
of COPD Patients
Associations



Contents

- 2 The economic burden of COPD
- 3 The personal burden of COPD
- 4 Understanding the disease
- 7 Our Vision for Change
- 10 Conclusions of our Manifesto
- 11 The role of ENCPA
- 12 ENCPA associations that approved the Manifesto

Introduction

Fundamental to the mission of the European Network of COPD Patients Associations (ENCPA) is raising awareness of Chronic Obstructive Pulmonary Disease (COPD): its causes, symptoms and progressive nature. ENCPA is a collaborative group of COPD patient associations across Europe and is an integral part of the European Federation of Allergy and Airways Diseases Patients Associations (EFA). We believe that increased awareness is the first step in ensuring COPD patients are diagnosed earlier and receive appropriate treatment sooner.

GOLD (the Global initiative for Obstructive Lung Disease) considers COPD a major public health problem and believes that COPD fails to receive adequate attention from the healthcare community and government officials.¹ In fact some estimates suggest that up to 600 million people worldwide may currently suffer from COPD.²

In Europe estimates suggest that up to 10% of the population may have COPD.³ It is currently the fifth leading cause of death⁴ and is predicted to rise. According to WHO figures the disease is the fastest growing cause of death in the world's advanced economies and is projected to rank third by 2020.⁴ In this respect, COPD is predicted to grow faster than all other lung diseases, including asthma and lung cancer.⁴

Yet surprisingly given these statistics, it is estimated that as many as 75% of people with COPD in Europe are undiagnosed and therefore experiencing untreated symptoms.⁵

So what is COPD? It is a disease state characterised by a progressive and disabling deterioration in lung function. The typical symptoms of COPD include persistent cough, chest tightness, shortness of breath and sputum production. These symptoms are often distressing, severely restricting a patient's ability to perform normal daily activities and significantly affecting their quality of life.¹

The purpose of this manifesto is to challenge current standards of COPD awareness and treatment and call on healthcare professionals and policy makers to work with us to realise our vision for change, improving the lives of those with COPD across Europe.

Mariadelaide Franchi
ENCPA Project Co-ordinator

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The economic burden of COPD

COPD is the fastest growing cause of death in the world's advanced economies.³ Such is the scale of the disease that the World Health Organisation predicts it will be the third leading cause of death in the developed world by the year 2020 – faster growing than lung cancer, heart disease and stroke.⁴ The disease has reached epidemic proportions. It is estimated that up to 600 million people may suffer from COPD worldwide.²

Dr Khaltsev, WHO, Non-communicable diseases programme, explains: *'COPD is a major economic burden for countries throughout the world and the projected rise in disease prevalence is extremely rapid. The WHO believes that reducing risk factors, raising awareness and improving diagnosis and treatment are key steps we must take to ensure that in the future the economic and personal burden of COPD can be lessened.'*

Smoking is the predominant risk factor for COPD, accounting for 80-90% of the risk of developing the disease.⁶ Rising rates of smoking have dramatically increased the levels of illness and death associated with COPD.⁶ This scenario is set to continue as the onset of COPD occurs after 20 to 25 pack years (a pack year is equivalent to 20 cigarettes smoked per day for one year). Other risk factors include high levels of pollution and exposure to a variety of airborne particles. Genetic factors may also be associated with a risk of developing COPD.¹ Although COPD has generally been considered to be more prevalent in men, current estimates project that in the future more women will be at risk of developing the disease, due to a rise in the number of female smokers.¹

Given its high prevalence, COPD causes a huge socio-economic burden to society compared with other disease states, especially other lung diseases.⁷ Progression of the disease usually results in patients experiencing complications or more frequent and severe exacerbations associated with the condition.¹ Patients experiencing these exacerbations, which include lower respiratory symptoms such as coughing, wheezing and shortness of breath (known as dyspnea), usually require a visit to their doctor, emergency attention or hospitalisation,¹ all of which impact on the economic burden associated with COPD care.^{8,9}

The personal burden of COPD

As the disease usually develops gradually and generally affects people over the age of 40, symptoms are often attributed by those with COPD to be a natural part of the ageing process.¹⁰ This often leads to patients presenting with severe symptoms, resulting in diagnosis occurring in the later and more disabling stages of the disease. Therefore many COPD patients fail to receive appropriate treatment and support in the earlier stages. In many cases, COPD is misdiagnosed as asthma which can also result in inappropriate treatment.¹

The most significant burden associated with COPD is carried by the sufferer themselves – impacting considerably on their quality of life.¹¹⁻¹³ Fatigue, commonly aggravated by sleeping disturbances, and dyspnea can not only severely limit physical activity, but in turn can also impact on a patient's economic and social roles.^{12,14} The symptoms experienced can also have a psychological impact – people with COPD frequently experience feelings of anxiety, hopelessness and depression.^{14,15}

Because of the chronic nature of the disease and disabling symptoms associated with it, carers are often forced to take on considerable physical, social and emotional responsibilities when caring for relatives and friends.¹⁶

Understanding the disease

The term COPD encompasses both chronic bronchitis and emphysema.¹⁷ Typical symptoms include shortness of breath, cough, wheezing and increased sputum production, the most common symptom is characterised by breathlessness on physical exertion.¹ COPD is a progressive disease, many people living with COPD experience deconditioning, as their ability (and sometimes motivation) to perform everyday tasks becomes increasingly compromised.

COPD is often misdiagnosed as asthma or goes undiagnosed in its mild and moderate stages.¹ As a disease that generally strikes after the age of 40, symptoms are often first attributed to ageing, therefore patients often do not present until symptoms are severe.⁶

Diagnosis of COPD is based on an assessment of risk factors (eg. smoking, exposure to pollutants) and symptoms and is then confirmed with spirometry (lung function testing).¹

To aid diagnosis and management of COPD, the disease is often sub-divided into stages depending on severity – characterised by lung function (FEV₁) as well as clinical signs and symptoms. According to GOLD there are four stages to the disease, characterised as: at risk, mild, moderate and severe.¹ In its later stages the symptoms of COPD can be deeply debilitating, restricting a person's ability to lead an active life and perform normal daily activities.^{12,14}

Due to its progressive nature early diagnosis and treatment of COPD is essential for prevention of complications and exacerbations (worsening of symptoms) associated with the condition.¹ The onset of these complications and exacerbations often results in hospitalisation or the need for emergency care.¹ This has major consequences regarding quality of life as well as increasing the costs associated with care.¹

Although lost lung function cannot be regained by means of current interventions, smoking cessation has been shown to reduce mortality and slow the rate of lung function decline.^{18,19} In addition, recent pharmacological advances offer hope by alleviating symptoms of COPD and can significantly improve quality of life for some patients.

The following quotes – from real people living with, or affected by the disease – further help us understand the impact it has on life and the hope provided by proper support:

‘When I found out about my lung condition I thought my life was over, but joining a local support group turned my life around. It gave me a reason for getting out of bed’

Jenny, UK

‘As soon as I found the courage to speak to a pneumologist about my shortness of breath, and was diagnosed and received treatment; my life became so much easier’

Edoardo, Italy

‘When my doctor told me I had COPD, I didn’t even understand the term. This made the diagnosis all the more worrying for me and my family. For me, better understanding of the disease both by doctors and patients is really important’

Harry, Norway

'I just thought I was getting older, that my breathlessness was something I had to learn to live with. Now I realise that I had had COPD for some time. Treatment does make a difference, but I wish I had started it earlier'

Helena, The Netherlands

'Meeting other carers and families of those with COPD has really helped both me and my wife. Sharing our experiences and learning from others has given us a new and positive outlook on the future'

Tommy, Sweden

Our Vision for Change

Central to this manifesto for patients, ENCPA has developed and agreed the following seven key objectives which together form our call to action or 'Vision for Change'. It is our hope that all those involved in the management of COPD will work with us to achieve our aims:



Diagnosis and management of COPD

With the prevalence of this debilitating disease reaching epidemic proportions, clearly defined strategies for accurate and early diagnosis and improved management must be put in place.

These strategies must encompass:

- Improved diagnostic strategies, aimed at those patients in the earlier stages of the disease
- Increased and more widespread use of spirometry to confirm early diagnosis of the disease and hence improve management
- Optimum and safest care at every level, from primary care to specialist healthcare



Reduction of risk factors

Many of the risk factors for COPD are associated with lifestyle and environmental factors. We must therefore make people aware of the impact that their lifestyle may have on their own health and the health of those around them, encouraging prevention of COPD.

This will be achieved through:

- Widespread educational campaigns to increase awareness of risk factors such as tobacco smoke, occupational exposure to dusts and air pollution, to motivate those at risk of COPD in the future to take preventative steps
- Increased awareness and uptake of the influenza vaccine to assist in prevention of exacerbations and improvement in lifestyle and disease management



Programmes for training, education, empowerment and rehabilitation

Training and educational programmes are of critical importance in order to improve standards of care and address the current lack of knowledge regarding the diagnosis and management of COPD.

These training programmes should include:

- Improved and widespread training and education for doctors and other healthcare professionals
- Education and empowerment programmes for patients, including rehabilitation programmes
- Promotion of training about COPD for carers, employers and families of people with COPD



Safeguard COPD Patient Rights

Lack of knowledge and understanding of COPD may result in failure to recognise the needs of people living with the disease.

We therefore need to:

- Define and defend the rights of people living with COPD
- Promote standards of care and quality of life for people living with COPD, their families and carers
- Campaign for equal access to treatment, information, education, prevention and pulmonary rehabilitation programmes for all COPD patients and their families



Build patient unity

As quality of life is so profoundly affected by COPD, people living with the disease need to feel supported and reassured that they are not alone. Bringing patients together will remove feelings of isolation and encourage interaction with other people living with COPD.

ENCPA believes this can be achieved through:

- Provision of reassurance and support for people with COPD through improved access to patient groups, support networks and tailored educational materials



Financial and social support

In order to ease the financial and social burdens carried by people living with COPD and their families, strategies for providing support at a local level must be put in place.

These strategies will provide:

- Improved financial and social support for care of people with COPD in order to improve management of the condition and rehabilitation in hospital and at home



Commitment to research

Improvements in COPD management must be matched by an ongoing research commitment into the epidemiology, burden and pathogenesis of the disease. Additional research should focus on how best to reduce risk factors, minimise exacerbations and slow the progression of the disease, as well as the issues surrounding improved diagnosis and management of COPD.

We therefore call for:

- Further research into epidemiology of COPD
- Further research into the impact of tobacco smoke and the health consequences associated with it
- Increased investment in research into the pathogenesis of COPD
- Further research into the impact of COPD on quality of life and day-to-day living for people with COPD, their families and carers
- Identification of more effective management strategies for COPD resulting in improved quality of life

Conclusions of our Manifesto

The rights of COPD patients, now and into the future, must be equal to the rights of patients with other conditions.

- The right for information about the condition
- The right for support and understanding
- The right to receive early and accurate diagnosis
- The right to receive optimum standards of care and treatment
- The right for continued research and investment to improve future standards

We believe that the challenges outlined in ENCPA's 'Vision for Change' safeguard and build on the existing rights of COPD patients and the standards of support and care they receive.

By working together with healthcare professionals and policy makers ENCPA believes that our vision can become a reality.

Rome, October 2002.

The role of ENCPA

ENCPA is a collaborative organisation set up to help co-ordinate the efforts of patient organisations across Europe in providing information, assistance and support to people who live with COPD. ENCPA is an integral part of the European Federation of Allergy and Airways Diseases Patients Associations (EFA).

Since the prevalence and burden of COPD is predicted to rise, ENCPA believes that there is a need for urgent action to raise awareness of COPD and improve diagnosis, treatment and prevention of the disease. The current lack of knowledge regarding the condition is a major barrier to ensuring optimal standards of diagnosis and care and improving the rights of patients.

Key aims of ENCPA:

- To safeguard and improve the quality of life for patients with COPD
- To improve the knowledge, support and treatment for people living with COPD in Europe
- Increase patient expectations towards better management of COPD
- Increase public understanding of COPD
- Increase awareness about the burden of COPD and raise commitment among healthcare professionals and health policy decision makers to improve information, diagnosis, management and prevention of the disease, including tobacco cessation programmes
- To promote co-operation with other COPD patient associations worldwide
- To build relationships with key stakeholders to achieve our goals
- To protect future generations against COPD

ENCPA associations that approved the Manifesto

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