

Press Release 05/12/2013

Standards of Care for COPD patients are not equal in Europe

EFA reveals the state of play and releases Minimum Standards of Care to enable active patients participating in society

COPD is a serious lung disease and will become the third leading cause of death by 2020, but how do patient associations view the care and preventative actions in Europe? EFA conducted a survey in 16 countries in Europe through its member associations on care as well as prevention and published the results in its *EFA Book on Minimum Standards of Care for COPD Patients in Europe*. The book was first presented at an event in Brussels on November 28th 2013 under the auspices of the Lithuanian EU Presidency.

Care and prevention for COPD is inconsistent: in Poland, the healthcare system does not fund smoking cessation services, even if tobacco smoke is the primary cause of COPD, and in many other countries they are free only for people at risk. In Austria, diagnosis is often made too late, and spirometry tests to diagnose COPD are not part of the annual health check-ups. In Italy, not all patients can access rehabilitation, which is key to keep patients active. In Portugal there are even shortages of medicines because of the economic crisis, whereas in Finland it has led to difficulties in transferring patients from specialist to GPs.

"Early diagnosis is the single most effective measure to take, followed by care that supports independence of patients" EFA President Breda Flood said. "This book is a tool for policy makers, healthcare professionals, patient groups and other interested parties to gear towards 'solving COPD' especially in this economic situation where every cent spent must create value for society. Active patients are valuable!" The EFA COPD project Medical Advisor, Professor Jorgen Vestbø, former chair of the scientific committee for the Global Initiative for Chronic Obstructive Lung Disease (GOLD) confirmed and said that "It is astonishing to see the variability of how differently COPD diagnosis and management is performed across Europe and this variance could very well be an indicator of poor care for patients. This also points to an obvious need for earlier diagnosis."

Michael Wilken, a COPD patient and Chair of EFA's COPD Working Group emphasized that "Patient involvement in healthcare design equals effective care that takes into account co-morbidities, in COPD, these include anxiety and depression, heart disease, osteoporosis. Today, patient involvement varies greatly in the 16 countries surveyed".

As a result, EFA pinpointed 8 key interrelated areas which together provide a basis for patient-centered and minimum standards of care:

- 1. Ensure early diagnosis of COPD by using spirometry testing in primary care for current and ex-smokers older than 35 years old;
- 2. All general practitioners should be adequately educated to administer spirometry testing and interpret the results so as to assure early and accurate diagnosis;
- 3. Coordination should be increased between primary care, specialists and hospitals to increase efficiency of treatment and quality of life for patients;
- 4. Smoking cessation services and pulmonary rehabilitation should be made available for all COPD patients in need, regardless of their employment status;
- 5. Increase the number of centres for COPD care and rehabilitation and ensure there are systematic plans in place for how to avoid exacerbations, consistent follow-ups with patients and intensive up-to-date training on the self-management of the condition;

- 6. Promote a multidisciplinary approach for the rehabilitation of COPD patients to involve all necessary medical professionals who can help improve their quality of life with comorbidity assessments so as to efficiently treat all COPD patients;
- 7. The participation of COPD patients should be legally embedded in all government decisions or processes directly affecting COPD patient care;
- 8. Alpha-1 Antitrypsin Deficiency, rare genetic condition that can cause COPD, testing should be available for infants and pregnant women at risk and augmentation therapy (AT) in all European countries with the possibility of reimbursement.

The book also underscores best practices which could help to improve the existing gaps in care and uses EFA's eight requests above as a starting point for change.

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Notes to editors:

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) is a non-profit network of allergy, asthma and COPD patients organisations, representing 35 national associations in 22 countries and over 400,000 patients. EFA is dedicated to making Europe a place where people with allergies, asthma and COPD have the right to best quality of care and safe environment, live uncompromised lives and are actively involved in all decisions influencing their health. www.efanet.org

An electronic copy of the EFA book Minimum Standards for COPD Care in Europe is available for download on EFA's website here and the order of printed copies are available from the EFA office info@efanet.org.