

# "Longcentra Nederland - Bijeenkomst tijdens ERS Conferentie"

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From the Patient Point of View:

## **Proposals for an improvement of better care for COPD patients**

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We know much about COPD - especially about Comorbidities.

But this does not find a sufficient reflection in the existing care system.

The main gaps between knowledge and reality are:

- Prevention
- Early diagnosis
- Cooperation between Pneumology, Kardiology, Psychiatry, Diabetology and others
- Rehabilitation.

We had no data about the situation in Europe, so we did two studies:

„Minimum Standards of Care for COPD Patients in Europe“

[http://www.efanet.org/images/2014/10/EFA-Book-Minimum-Standards-of-Care-for-COPD-Patients-in-Europe\\_ENGLISH.pdf](http://www.efanet.org/images/2014/10/EFA-Book-Minimum-Standards-of-Care-for-COPD-Patients-in-Europe_ENGLISH.pdf)

„Harmonizing Prevention and Other Measures for COPD Patients Across Europe“

<http://www.efanet.org/images/2015/04/EFA-2014-SURVEY-%E2%80%93-Harmonizing-Prevention-and-other-Measures-for-COPD-Patients-across-Europe.pdf>

## Some essential points:

- EFA acknowledges the care situation and awareness of chronic obstructive pulmonary disease (COPD) has improved for COPD patients over the past years. Nevertheless, progress does not mean consistency of the care exists across all of Europe or that the situations for all COPD patients have improved. The results collected in 2013 from EFA members uncover significant areas for improvement.
- The fact is that there is a wide range of healthcare systems in Europe, because healthcare is a sovereign competency of EU Member States.
- The health coverage and treatment that COPD patients receive differs from one country to another. Astonishingly, we found out that in countries like Italy and Finland, COPD has not been yet officially recognised as a chronic disease, a situation that poses real burden for COPD patients that might be paying higher for their care just because of this recognition.
- From the patient's point of view, it can be concluded that a comprehensive treatment must pay much more attention to psychosocial aspects, especially to psychiatric co-morbidities.

As a result of our studies, we pointed **8 key interrelated areas** which together provide a basis for patient-centered and minimum standards of care:

- Ensure early diagnosis of COPD by using **spirometry testing in primary care** for current and ex-smokers older than 35 years old;
- **All general practitioners should be adequately educated** to administer spirometry testing and interpret the results so as to assure early and accurate diagnosis;
- **Coordination should be increased between primary care, specialists and hospitals** to increase efficiency of treatment and quality of life for patients;
- **Smoking cessation services and pulmonary rehabilitation should be made available for all COPD patients in need, regardless of their employment status;**

- **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;
- **Promote a multidisciplinary approach for the care and 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;**
- The participation of COPD patients should **be legally embedded** in all government decisions or processes directly affecting COPD patient care;
- **Alpha-1 Antitrypsin Deficiency testing should be available for infants and pregnant women at risk and augmentation therapy (AT) in all European countries with the possibility of reimbursement.**

- In the Netherlands the most important of our proposals is realised: we find a unique situation with six centers with dedicated multidisciplinary rehabilitation programmes.
- We hope that the situation in the Netherlands will have a lighthouse effect for all other countries in Europe!