

Lung foundation Australia: promoting lung health and supporting those with lung disease

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J Thorac Dis 2013;5(4):572-577. doi: 10.3978/j.issn.2072-1439.2013.08.39

Lung Foundation Australia (LFA, formerly known as The Australian Lung Foundation, Figure 1) is a national, not-for-profit organisation with a vision to make lung health a priority for all in Australia. LFA achieves this through programs, initiatives and activities and by partnering with other organisations to share resources and minimise replication of services. All LFA's activities, programs and initiatives revolve around at least one of the following:

- Advocacy;
- Awareness;
- Education and training;
- Patient Support;
- Research.

The COPD National Program and Lung Cancer Programs are the two largest programs within the Lung Foundation. These programs and other activities are well supported by the Lung Foundation's Information and Support Centre. The Information and Support Centre operates a toll-free number for patients, carers and clinicians to call and speak with one of the team (who can assist them to obtain resources and link to support services), or to speak with a Lung Care Nurse. Other key Foundation project areas include: Respiratory Infectious Disease; Interstitial and Orphan (Rare) Lung Disease (including an IPF and Bronchiectasis registry); Multi-Centre Clinical Trials Network, Australian Lung Cancer Trials Group, Telephone support groups and Community Awareness Events.

Facts about COPD in Australia

LFA estimates that approximately 1.2 million Australians have some form of COPD (1). This represents approximately 13% or

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Submitted Mar 17, 2013. Accepted for publication Apr 16, 2013.

Available at www.jthoracdis.com

ISSN: 2072-1439

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Figure 1. Lung Foundation Australia.

one in seven Australians over 40 (2).

7.5% of Australians 40 or over have COPD that has progressed sufficiently to where symptoms may already be present and affecting daily life. Half of these people will not know they have it and therefore are not taking the important steps to slow down the progression of the disease (2).

Nearly 520,000 Australians (1,2) have a mild form of COPD where symptoms may not yet be present. Many of these will go on to develop more severe COPD.

Australia has one of the highest rates of COPD deaths in the developed world—Australian mortality rates place Australia in the bottom third of the 34 OECD countries (3).

In Australia, despite falling death rates, COPD is still a leading cause of death and disease burden after heart disease, stroke and cancer (3).

COPD is the second leading cause of avoidable hospital admissions in Australia (4).

COPD national program

The COPD team accepts clinical guidance from a number of

committees established to advise on specific resources and program areas across the continuum of care. Dozens of clinicians across the country volunteer their time and knowledge to develop resources that are then distributed by the Lung Foundation. The COPD National program, led by Professor Peter Frith, Professor Christine MacDonald, Associate Professor Ian Yang, and Dr Kerry Hancock, currently centres its activities around five key areas.

Clinical awareness, education and training and supportive resources

The COPD National program has developed a number of clinical resources and training opportunities for primary care through to tertiary care providers to help them manage care for their COPD patients.

COPD-X plan

LFA proudly manages the Australian and New Zealand online management guidelines for Chronic Obstructive Pulmonary Disease, developed jointly with The Thoracic Society of Australia and New Zealand and the Lung Foundation under the clinical guidance of the COPD Evaluation Committee. These web-based guidelines for general practice are fully updated twice per year, and the committee convenes four times per year to evaluate new evidence as it's published. The guidelines act as a decision support aid primarily for general practitioners and other primary health care clinicians managing patients with established COPD. To increase use of these guidelines, they have been translated into a single page document, Stepwise Management of Stable COPD, which shows a stepwise guide to pharmacological and non-pharmacological interventions according to level of severity of disease. (<http://lungfoundation.com.au/professional-resources/guidelines/stepwise-management-of-stable-copd/>). A handbook that will translate the guidelines and provide recommendations for general practice is currently being developed and due for release July 2013.

Primary care respiratory toolkit

This online toolkit (<http://lungfoundation.com.au/professional-resources/1692-2/general-practice/primary-care-respiratory-toolkit/>) supports lung health promotion, early diagnosis and best practice lung disease treatment by combining the tools and information needed in the primary care setting to case find, diagnose and manage COPD. The toolkit contains instructions for targeted case finding (refer COPD Screening in the Community below), diagnostic testing for those at risk (i.e., spirometry), a lung age estimator (to use as a motivational tool) and COPD-X Aid and Stepwise management of Stable COPD.

COPD action plan

This guides the patient in recognising when their condition

changes and what action they should take and should be completed by the clinician and patient together. It lists their medications and action plan in the event of exacerbation (<http://lungfoundation.com.au/professional-resources/1692-2/general-practice/copd-action-plan/>).

COPD online training for practice nurses

A committee of experts combined their knowledge to build an interactive online training program to up-skill practice nurses on COPD. Nurses can identify and better manage patients with COPD and learn how to develop self-management programs (<http://lungfoundation.com.au/professional-resources/training/copd-nurse-training-online/>).

COPD symptom check flyer and poster

Designed to be displayed in surgery waiting rooms, patients who can say yes to three symptoms listed on a simple checklist are asked to speak to their doctor about their lung health.

Breathe easy, walk easy-pulmonary rehabilitation for rural and remote areas

This evaluated, face-to-face train-the-trainer style program trains health professionals in rural and remote communities to deliver evidence based pulmonary rehabilitation. Originally piloted in Indigenous communities, this bare basics approach to pulmonary rehabilitation is suitable for resource-limited health centres.

Pulmonary rehabilitation training online

An online training platform has been developed to up-skill allied health professionals including physiotherapists, exercise physiologists and nurses to deliver evidence based pulmonary rehabilitation, enabling those in remote areas to access best practice training. <http://lungfoundation.com.au/professional-resources/training/>.

A manual for pulmonary rehabilitation and the pulmonary rehabilitation toolkit

This free resource outlines how health professionals can set up a pulmonary rehabilitation program (www.pulmonaryrehab.com.au).

COPD pharmacy online training

This interactive program provides community pharmacists with advice about COPD and how to conduct targeted case finding and how to perform medicine reviews for disease state management. <http://lungfoundation.com.au/professional-resources/training/>.

Lungs in action

This online training program up skills exercise to safely supervise respiratory and heart failure patients in a weekly exercise post rehabilitation program (www.lungsinaction.com.au). Please visit



Figure 2. Lungs in Action.



Figure 3. A COPD patient is exercising during a Lungs in Action class.

the above web addresses for more information and to download resources. There is a fee for online training but many other resources are free.

Patient support

The COPD patient taskforce is a national forum for patients and

carers to provide guidance for the Lung Foundation on its COPD National Program. Two to three representatives from each state teleconference monthly to progress projects determined at the start of each year and to provide patient feedback on Lung Foundation programs. This taskforce is convened in conjunction with the COPD Program Director who links taskforce activities to the COPD National Program activities.

Numerous resources have been developed to support patients which can be downloaded from our website (<http://lungfoundation.com.au/lung-information/patient-resources/educational-resources/>) including disease specific fact sheets and the extremely popular “Better Living with COPD—A Patient’s Guide”. Our quarterly publication, Lungnet News, is sent to over 15,000 subscribers and provides relevant articles and tips. Our Information and Support Centre provides patients and carers with resources and can link patients with one of the 250 plus pulmonary rehabilitation programs across the country and the almost 100 maintenance exercise classes (including Lungs in Action programs). A database of 110 support groups is maintained and assistance is offered to set up new groups.

Lungs in Action (Figure 2) is a community based exercise maintenance class, taken post rehabilitation by those people with stable chronic lung disease and stable chronic heart failure and is fast becoming the new version of the patient support group. There are currently 55 classes each week across five states of Australia, providing much needed social interaction. A picture of a COPD patient exercising during a Lungs in Action class is shown (Figure 3) A summary of the features of the Lung in Action programs is provided below.

A range of Lungs in Action models have been shown to be successful and sustainable, but they all have several things in common:

- I. Affordable to the client and in an accessible location;
- II. Supported by the local pulmonary rehabilitation program;
- III. A good professional relationship between the Lungs in

Action instructor and the referring rehab program;

- IV. Program is set up to compliment an existing business and is not a stand alone program.

The pulmonary rehabilitation program at the Mornington Peninsula in the state of Victoria actively recruited Lungs in Action instructors to provide four programs within their health service district. They utilized a local government subsidized facility for one program and a personal trainer (who has a father with a lung condition) to run another program at a gym and also at a community hall. Patients pay \$6 pp to attend weekly which is affordable for lower income clients. A group of accredited exercise physiologists were also recruited to run a program for private hospital patients who are more affluent and who have health insurance to subsidize the higher cost of this style of program. The rehab providers and the Lungs in Action instructors meet monthly to discuss issues and keep up communication.

In the small town of Colac in Victoria, the local patient support group were proactive in establishing their own Lungs in Action program. They approached their local fitness centre requesting two instructors be trained to deliver Lungs in Action. The group then fundraised to cover the cost of the training and sought support for instructor mentoring from their local rehabilitation program. The Lungs in Action instructors visit each new rehab group to introduce themselves and invite the new participants to their community based Lungs in Action program.

On the Gold Coast in Queensland, the local government has supported the Lungs in Action programs through small community grants which pay for the cost of hiring the community halls and/or contribute a small amount towards the instructor fee. The patients pay \$5 to participate in order to supplement the remainder of the program costs. Community focussed groups such as the Police Citizens Youth Club and Community nursing groups have established Lungs in Action programs with this support.

In Brisbane a local patient support group, the Wilston Windbags sought the support of their local scouting group. The scouts provide their den for the weekly class and have fundraised to buy exercise equipment which is stored within the scout hall. The groups' instructor visits each week to run the class and afterward the support group has a cup of tea. They invite speakers monthly to talk on topics of interest to the group.

Two universities have also established Lungs in Action programs in their clinics. The senior lecturers underwent Lungs in Action training and then supervised final year exercise physiology students to assist with the delivery of the program. This has proven to be a very successful model as patients have access to ongoing low cost maintenance exercise and the students have exposure to patients with chronic disease.

New patient support projects being worked on include a

series of short films aimed at self-management, a position paper for supportive and palliative care and end of life discussions in malignant and non-malignant lung disease.

Community awareness

2013 is an exciting year for LFA as it will be the launch of our largest campaign to date focusing on the *Lung Health Checklist*. This checklist of symptoms and risk factors has been developed to assist with targeted case finding and is available in several languages. Answering yes to three or more symptoms prompts patients to speak with their doctor about their lung health. The checklist is supported by the use of *COPD Screening Devices* (supporting resources, training tools and videos for the use of screening devices can also be found on our website). (<http://lungfoundation.com.au/professional-resources/1692-2/community-pharmacy-new/>).

The World COPD annual event in November is an opportunity for the COPD team to encourage people to participate in activities to raise awareness for COPD with approximately 120 events held nationally. A picture of COPD patients walking as a part of the LFA observation of World COPD Day is shown (Figure 4).

Presentations are provided to community nurses to deliver training to personal care workers, allied health assistants, patients and other health professionals in the community. Presentations to university students, NGOs, community organisations and corporations are also given. Community Awareness and Education activities are supplemented with a range of DVDs, Speaker kits and website based patient stories.

The Lung Foundation conducted a Newspan survey that unearthed the fact that whilst 84% of respondents aged 35 and over rated the health of their lungs as excellent, very good or good, one in three (36%) of them revealed they experience at least one of the signs of poor lung health. Another staggering result of the survey showed that 36% felt their lungs were unimportant. The "Show Us Your Lungs" Campaign took a slightly irreverent and somewhat controversial approach to community awareness campaigning in an effort to get Australians to take their lung health seriously. Models wearing underwear, were painted with body art showing either healthy or diseased lungs and were used to "flash" pedestrians in busy train stations and then spoke to interested members of the public about lung disease. This campaign was supported with television commercials and engaged radio celebrities such as Dr John Darcy (Figure 5) and actor John Jarratt (Wolf Creek).

Advocacy

We have formed alliances, strategic partnerships and increased our participation in key networks to increase attention to the importance of lung health. Recent health reforms have



Figure 4. COPD patients are walking as a part of the LFA observation of World COPD Day.



Figure 5. Dr John Darcy, a radio celebrity, is engaged in this campaign.

increased the complexity for our and other lung disease specific organisations to be heard by key decision makers, making these alliances critical.

Currently, the COPD National program advocates for increased access to pulmonary rehabilitation and ongoing exercise maintenance.

COPD facts in Australia

In 2008, the total economic impact of COPD was estimated to be \$98.2 billion of which \$8.8 billion was attributed to financial costs and \$89.4 billion to the loss of wellbeing (5).

- Of the financial costs (\$8.8 billion), a large proportion

is due to the loss of productivity due to COPD, ie lower employment, absenteeism and the workplace impact of premature death of Australians with COPD (5).

- The direct cost to the Australian health care system is estimated to be \$900 million with hospital use contributing the largest share of health spending (\$473 million) (5).
- In addition to the above costs on the public and private sector purse, there are the costs that are harder to quantify—those of lost wellbeing as a result of COPD. These are estimated to be some \$90 billion (5).

In terms of overall costs, COPD is more costly per case than cardiovascular disease, osteoporosis or arthritis (5).

Research

An annual COPD Research Fellowship is awarded to an individual for research into COPD that can be translated from bench top to bedside. Applicants are reviewed by the Thoracic Society of Australia and New Zealand and a winner chosen.

Acknowledgements

Disclosure: The author declares no conflict of interest.

References

1. Based on ABS census data--CData Online 2006 Census, Australian population over 40. Available online: <http://www.lungfoundation.com.au/professional-resources/statistics/copd-the-statistics/>
2. Toelle BG, Xuan W, Bird T, et al. COPD in the Australian burden of lung disease (BOLD) study. ATS 2011: Abstr A1733.
3. AIHW. eds. Australia's health 2012. Australia's health no. 13. Cat. no. AUS 156. Canberra: AIHW, 2012.

4. Page A, Ambrose S, Glover J, et al. eds. Atlas of avoidable hospitalisations in Australia: ambulatory care-sensitive conditions. Adelaide: The University of Adelaide, 2007.
5. "Access Economics," Economic Impact of COPD and cost effective solutions. 2008.



Cite this article as: Harper E. Lung foundation Australia: promoting lung health and supporting those with lung disease. J Thorac Dis 2013;5(4):572-577. doi: 10.3978/j.issn.2072-1439.2013.08.39