

British Lung Foundation: setting up expert patient peer support groups

Summary

Sustainable and professionally supported volunteer-led peer support groups, with links to health and care services, are increasing self-management, reducing feelings of social isolation and addressing health inequalities. For people with multiple conditions, which 90% of people with lung disease have, there are monthly support groups and weekly exercise and activity groups.



Main points

- Pilot in Stoke-on-Trent explored creating a more structured programme for peer support groups
- Funding through Nesta's Accelerating Ideas programme with the National Lottery Community Fund established a dedicated team to work with volunteers to create local support groups and provide training and advice for 18 months
- The British Lung Foundation (BLF) work closely with council and NHS teams in each area to bring in their expertise
- Telephone advice available once 18-month hands-on support ends
- Programme in middle of second phase of roll-out

*"PEOPLE BECOME REALLY PASSIONATE
ADVOCATES AND LEADERS FOR PEER
SUPPORT WITH THE RIGHT SUPPORT,"*

*— LISA WILLIAMS, SENIOR
INTEGRATED BREATHE EASY PROJECT
MANAGER*



Context

While mortality from heart disease and some non-respiratory cancers is falling, rates of death from lung disease haven't improved for 10 years. It is now the nation's third biggest killer.

For those living with a lung condition, daily life can be a struggle. Symptoms such as breathlessness can be frightening and difficult for people to manage alone. Everyday tasks such as walking up the stairs become a huge challenge.

People living with lung conditions are also often affected by complex health issues. Nine in 10 people

with chronic obstructive pulmonary disease (COPD) – the most common lung condition after asthma – have multiple conditions. This often causes anxiety and inactivity, causing people's health to deteriorate faster. People become socially isolated and lonely. Unfortunately, many often accept their symptoms as inevitable.

Lung disease is also a major factor in widening health inequalities. COPD is twice as prevalent in the most deprived fifth of the population as the least deprived.

Lung conditions are one of the most common long-term illnesses.

Around 12 million people in the UK are living with lung disease.

What was done?

Since the 1990s the BLF has been helping to establish community peer support groups for people living with lung conditions.

These groups have proved popular but can struggle to remain sustainable, have varied in style and format and have not always fully integrated into the local health and care system.

In 2011 the BLF started working with the NHS in Stoke to create a more structured integrated system of peer support, which led to the charity gaining £397,000 of funding from Nesta and the Cabinet Office's Centre for Social Action Fund for a two-year project to develop and test the Integrated Breathe Easy (IBE) programme.

The BLF set up a dedicated team to work in local areas to set up peer support groups. The three-strong team of project managers are embedded in communities working with people living with lung conditions and their carers and local health professionals to fully establish support groups over an 18-month cycle that then become self-sustainable.

The aim is to set up monthly support groups attended by speakers such as doctors and nurses along with regularly weekly exercise and activity

groups, including singing, chair-based exercise and Tai Chi to support people's holistic health and wellbeing.

Volunteer leaders, who have lung conditions themselves, are identified to run the groups and fulfil roles such as chair or treasurer. They are given training in skills such as local fundraising and booking exercise instructors and speakers and are given some seed-funding to get the groups off the ground.

Once the groups are up-and-running, they start asking for small donations from participants to cover their costs, such as venue hire, with speakers often volunteering their time for free. Some have also applied to local charitable trusts for help towards costs of additional activities, supported by BLF's fundraising team.

These groups were formerly called Integrated Breathe Easy (IBE) groups, but have recently been re-branded as BLF Support Groups. Based on the success of this roll-out, Nesta and the National Lottery Community Fund granted the BLF a further £958,309 to support a national roll-out of IBE. This is a five-year project of which the charity is in year four.

What has been achieved?

The initial two-year project saw 40 different groups set up across the UK – all of which still exist and the current national roll-out has delivered a further 46 groups. The groups are in urban and rural locations in all four constituent countries of the UK.

Group sizes ranged from 10 to 50 people. While the work is focussed on respiratory illness, the majority taking part have multiple conditions.

Feedback has been sought regularly to monitor impact. This is done when the group first starts and then six months later. It commonly shows close to 100% of respondents report their health has improved. An evaluation study by the University of Kent showed a 42% reduction in GP appointments and a 57% reduction in unplanned hospital admissions.

Meanwhile, an analysis carried out by New Philanthropy Capital in year two of the work found encouraging signs the work was addressing health inequalities. The benefits seen were greater in areas where the groups reached the most deprived people.

Overall, an evaluation of the groups set up between 2014 and 2016 found for each £1 invested there was a minimum return of £5.36 through better health outcomes, such as reduced hospital admissions. The experience of Joan, a member of the East Lothian Breathe Easy group, is typical of those who have been helped. She is 68 and has had lung cancer, which left her with scarring on her lungs. Joan also has rheumatoid arthritis.

Before joining Breathe Easy, she said she was struggling having stopped swimming, leaving her feeling isolated.



She says the group has helped her make new friends and given her the confidence to manage her condition and find out what local health services are available to help her. She is now doing a weekly Tai Chi class. "Breathe Easy takes you away from yourself. It takes your mind somewhere else," she added.

Council strategic commissioning manager for long-term conditions Sarah Crouch said: "It was a great opportunity for commissioners to work more collaboratively with people with lung conditions alongside respiratory healthcare professionals.

"Although the project has now ended, collaborative relationships continue with the Breathe Easy group volunteers. They continue to be part of the local respiratory clinical leads network and we are jointly working together to raise awareness and improve the support provided to people living with lung conditions in East Sussex."

"BREATHE EASY TAKES YOU AWAY FROM YOURSELF. IT TAKES YOUR MIND SOMEWHERE ELSE,"

– JOAN, 68, PATIENT AND PEER GROUP MEMBER



“IT WAS A GREAT OPPORTUNITY FOR COMMISSIONERS TO WORK MORE COLLABORATIVELY WITH PEOPLE WITH LUNG CONDITIONS ALONGSIDE RESPIRATORY HEALTHCARE PROFESSIONALS”

– SARAH CROUCH, EAST SUSSEX COUNCIL STRATEGIC COMMISSIONING MANAGER FOR LONG-TERM CONDITIONS

What lessons have been learned?

Having on-the-ground support for 18 months clearly helps the development of the groups. Over time the team has developed a tried-and-tested method to give them the best chance of becoming sustainable.

One of the first steps is establishing a local planning group, which brings together partners from across the local area, including carers, commissioners and health professionals. This helps to ensure buy-in from the local health economy as well as harnessing their expertise.

To act as a springboard to engaging people, the project managers organise a respiratory information event, which is promoted locally, including through GP surgery mail-outs. The events give immediate advice and support to people on managing their health and wellbeing as well as sign-posting people through to the new group meetings.

Senior IBE Project Manager Lisa Williams says: “This has been the real strength of this approach – the ability to join up with the local health system and engage people. Once you have them on board and the links established you have a good chance of having a successful group. People become really passionate advocates and leaders for peer support with the right help.

“But we also make sure we provide them with on-going support. Towards the end of the 18-month cycle, the project managers start pulling away gradually. But when they have left the peer leaders can still access a central support team for telephone advice.”

What is happening now?

To help build on this on-going support, an online forum has recently been launched. Group volunteers are given login details, which they can use to access bespoke training modules, advice and guidance, and a forum to share experiences with other groups across the nation. This is allowing peer leaders to share ideas and ask questions of others involved in the work.

The work of the team is also continuing. The BLF is now preparing to expand into new areas, using what they’ve learned throughout the project. The aim is to carry out another evaluation of the work to help build the evidence-base for it.

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