

MEMBER CONTRIBUTIONS

Post-pandemic holistic breathless recovery - a social prescription for respiratory care



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Given the direct impact of COVID-19 on those with existing breathing difficulties, the 'newly breathless' – those whose lung function has been impaired by Covid – as well as rising levels of air pollution,¹ the need for social prescribing solutions in respiratory healthcare has never been greater.

BreathChamps CIC is a two-year-old innovative social enterprise, helping people and communities to learn and share breathing knowledge in fun and social ways. This article describes the learning from a range of research-based holistic social prescribing solutions for adults with long term respiratory conditions, funded by Trafford Housing Trust (THT).

Activities are complementary to clinical solutions, creating an extension to the current respiratory care pathway in Trafford, Greater Manchester. These include singing, walking, nature activities called forest bathing, crafting, creative writing/performing and breath awareness workshops.

Building on strengths

BreathChamps was built upon my lived experience of respiratory issues. Following years of uncontrolled asthma, two spontaneous pneumothoraces, a pleurectomy and excision of emphysematous bullae, at 21 years old I only had a third of my right lung capacity remaining. I trained as a cardiothoracic nurse to help others like me, followed by a career in primary care, both as a nurse and a senior manager.

Twelve years ago, I retrained in asset-based community development with a charity called Connecting Communities (<https://www.c2connectingcommunities.co.uk/>), which was then

hosted by Exeter University Medical School. I worked nationwide alongside many communities experiencing multiple disadvantages which reshaped my entire approach to nursing.^{2,3} BreathChamps changes the perception of 'patients', to citizen-partners who have agency and can become effective vectors of clinical and social knowledge,⁴ becoming the enabler of change, rather than the solution, connecting assets together and creating more resilient communities.

Evidence base

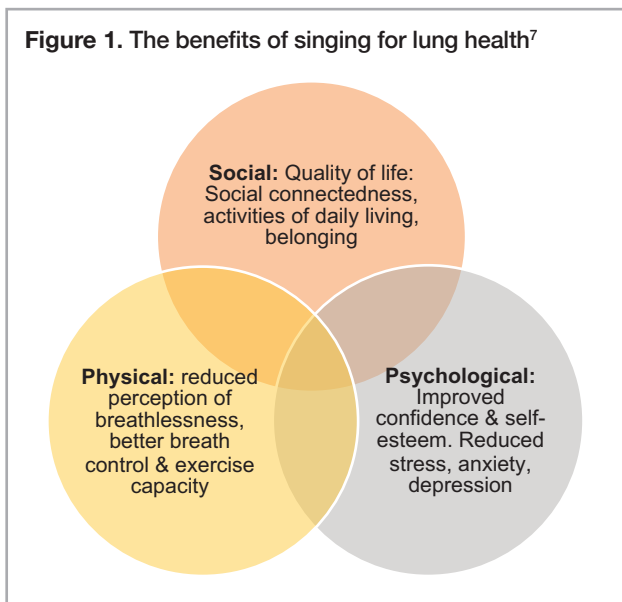
There is a strong psychosocial element to breathlessness. Like pain, it is subjective, involving both the person's perception of the sensation and their reaction to the sensation.⁵ The programme is based on the Life of Breath Project⁵ and the 'breathing thinking functioning' model⁵. These describe how respiratory disease changes how we feel and subsequently act. Essentially, objective measurement can be misleading and the perception of dyspnoea trumps reality (Figure 2).

Objectives

Solutions therefore focus on both the mind and the body. The objectives of the programme are to improve wellbeing associated both with breathlessness and also the legacy of the pandemic by:

- offering activities to get people out and moving more
- addressing anxiety
- enabling people to make social connections
- restoring meaning and purpose in life.

Figure 1. The benefits of singing for lung health⁷



Box 1: Benefits of nature-based activities ('green care' or ecotherapy)⁸

- Reduced depression, anxiety and stress related symptoms
- Improved in dementia-related symptoms
- Improved self-esteem, confidence and mood
- Increased attention capacity and cognition
- Improved happiness, satisfaction and quality of life
- Gave a sense of peace, calm or relaxation
- Increased feelings of safety and security
- Increased social contact, inclusion and sense of belonging
- Increased work skills, meaningful activity and personal achievement

Source: Natural England 2016

The Recovery Programme

Trafford Housing Trust administer grants to organisations like BreathChamps that offer community-based solutions to help the population recover from the effects of the Covid-19 pandemic. Table 1 summarises the components of the Breath-Champs recovery programme.

Learning by doing

BreathChamps uses an improvement cycle of plan-do-study-act (PDSA), conducting rapid tests to learn what works and what doesn't.

Through this we discovered that:-

- Wellbeing and dyspnoea scores have improved, apart from life satisfaction (table 1), which could be down to other factors, such as the cost of living.
- People are keen to partner and to volunteer. We exceeded our targets for volunteering, including for our board members, where we received 12 applications for 2 posts. Managing and enabling many volunteers to flourish is time-consuming but worthwhile, especially when we are all learning together.

- People are naturally reticent about joining things that they have never experienced, like forest bathing, singing or poetry, so we bring taster sessions to groups, so they know what to expect and have met staff or volunteers.
- Breathless people, sensitive to many environmental triggers, don't turn up for 'mini walks'. They will however push themselves to come to a nature activity that they have to walk to get to.
- Marketing via social media is limited. Direct contact, visiting and demonstrating activities to existing groups is more successful.
- Even though Trafford is perceived as more affluent than other parts of Greater Manchester, it still has low-income communities and many older people living on limited means. Activities need to be local as transport problems and digital exclusion occur often. Many rely on contact by phone, lifts and community transport.
- We don't charge for any activity (funded by THT) and this is sometimes interpreted as having less value, so drop outs occur, for example on singing courses. Breath-Champs is considering whether making a small charge of

Figure 2. The perception of breathlessness⁶

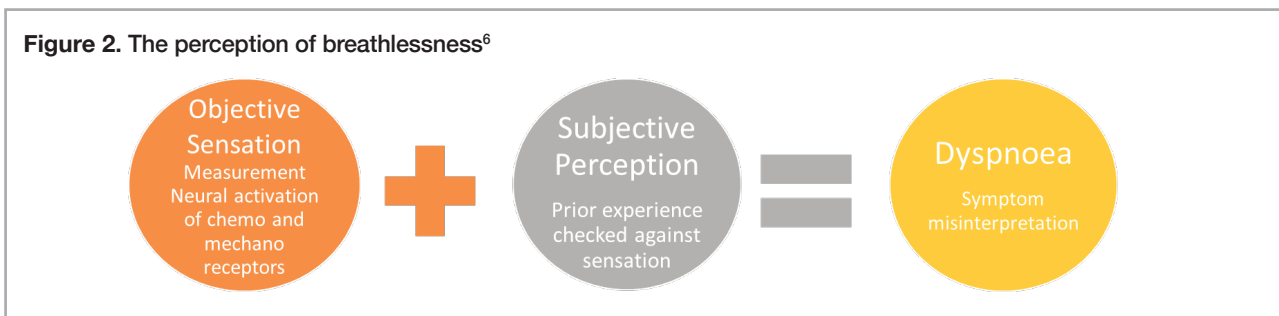


Table 1. BreathChamps Holistic Breathless Recovery Programme

Activity	Description	Progress	Measures	Outcomes to date
Singing for lung health courses co-located in a 3rd sector mental health or sheltered/ extra care housing settings	6-week courses, delivered by 1 nurse and 2 professional singing leaders trained to Asthma and Lung UK standards. Accessible venues across Trafford	Delivered in partnership with Simply Singing CIC, who have received training. 6 courses completed, 2 to complete.	Office for National Statistics personal well-being score (ONS4). Dyspnoea 12 score Modified Medical Research How far participants feel connected to their community	Scores at month 0 and month 3 (month 6 figures being collected) show: Marginally less <ul style="list-style-type: none"> • Levels of dyspnoea • Emotionally troubled by breathing • Satisfaction with life • Anxiety Similar <ul style="list-style-type: none"> • Life is worthwhile • Happy Marginally more <ul style="list-style-type: none"> • Connected to their community
Forest bathing (Shinrin Yoku) originating from research in Japan involving mini walks of 1/3 mile or less. Open to everyone especially those with life limiting illness and mental health issues	A form of ecotherapy, that uses all our senses to connect to, or 'bathe' in nature. A mindful practice that improves immunity and reduces the stress response by reducing cortisol levels and increasing natural killer cell activity ⁹	10 local volunteers recruited, including a GP and 3 nurses, who are completing an online diploma in forest bathing. One weekly and two monthly forest bathing sessions available in local parks	ONS4 How far participants feel connected to their community	Started later than singing. No hard data as yet. Observable changes – examples: Gentleman with idiopathic pulmonary fibrosis, on home oxygen therapy: has to stop twice and sit down on the journey of 900 paces from the meeting point to the wood. On the way back, he does not stop to rest. Lady with advanced kidney cancer: Had to be accompanied by social prescriber, very socially anxious and did not want to speak to anyone. She befriended another forest bather, a retired teacher who declared she was lonely. She now smiles, chats and tells us that 'I can really breathe here.'
Creative writing and speaking events that help people express their feelings	A resident poet visits community groups or hosts events to help people to express their feelings	Monthly events held with vulnerable groups across Trafford	Not formally measured	Don't tell me Don't tell me I can't smile Don't tell me I can't run a mile Don't tell me that you'll soon be well Don't tell me that things will be swell Don't tell me to keep my feet on the ground Don't tell me that a cure will one day be found Don't tell me that you understand Don't tell me to stay on the land Don't tell me to put on a brave face Don't tell me to accept things with grace Do tell me be who you want to be Do tell me that I'm like you and you're like me. <i>By Steve Moritz, with severe asthma (with permission)</i>
Crafting activities	Bring breathless and anxious people together, facilitating an open discussion about what	Activities include: 'Decorate and bag and save a life' – Children are invited to decorate cotton bags that	Not formally measured	'Decorate and bag and save a life' was run in partnership with Sale and District Lions Club in Sale Town Square, whose members had been <i>Continued opposite...</i>

Table 1. BreathChamps Holistic Breathless Recovery Programme continued

Activity	Description	Progress	Measures	Outcomes to date
	matters to them. Used as a way to share self-help information. Often happen in very public spaces like town centres	can be used to store inhalers and spacers. 'Make a model lung' from a plastic bottle and 'Bee Asthma Friendly' crafting activity focusing on pollen and hay fever.		trained to share correct inhaler technique and asthma first aid. Not unexpectedly during over 70 engagements with the public, we discussed <ul style="list-style-type: none"> • Over reliance on reliever inhalers • Incorrect technique • Device switching without advice
Breath awareness workshops	BreathChamps is invited to local voluntary groups and statutory agencies to cascade breath awareness knowledge and listen to the 'wisdom of the community'	A 1-hour session typically includes <ul style="list-style-type: none"> The size of the respiratory problem in UK The National Review of Asthma Deaths Asthma first aid Q&A on inhaler technique/demonstrations Over-reliance on reliever inhalers Breathing exercises: relaxed breathing, breathing rectangle. 	Evaluation of how confident people feel about supporting someone else with a breathing problem before and after the workshop	100% of attendees have reported improved confidence. Some knew 'some things' already and for others the knowledge they got was brand new.

£1-£2 or donations may address this. We also text people to explain the full cost of activities.

- Having fun is important – the work is highly relational and if people like the leader and enjoy an activity they are more likely to benefit and to come back.

Next Steps

We hope that the BreathChamps business model, over time, will become a national demonstrator site for our holistic programme. We plan to offer educational events to enable others to replicate our activities.

We also aim to consolidate our partnership with Trafford people and cascade our knowledge via train the trainer programmes, for example by teaching Trafford primary school teachers how to sing for lung health or match forest school activities with forest bathing. We will continue our work to enable the citizens of Sale, where the company is based, to make it the first 'breathing-friendly' town in the UK, where everybody looks out for and helps everyone else.

References

1. Environmental Protection UK (Online) <https://www.environmental-protection.org.uk/>
2. Henry, H (2019) Feature: Why we should be asking communities for help rather than giving it Nursing Standard 27th March
3. Henry H and Howarth, M (2018) An Overview of using an Asset Based Approach to Nursing. Journal of Community Nursing. Vol 4 No 4
4. NESTA, People Powered Results. <https://www.nesta.org.uk/project/people-powered-results/>
5. Spathis A, Booth S., Moffat C et al. (2017) The Breathing, Thinking, Functioning clinical model: a proposal to facilitate evidence-based breathlessness manage-

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- Background/Introduction
- Project outline
- Objectives
- Methods
- Results
- Conclusions
- Next Steps
- Implications for clinical practice/service delivery
- Implications of your project on the environment/greener healthcare

ment in chronic respiratory disease. Primary Care Respiratory Medicine 27:27 Available from <https://www.nature.com/articles/s41533-017-0024-z.pdf> (Accessed 05/10/2022)

6. Carel, H., Malpass, A., Binnie, K. et al. (2018) More than a medical symptom: the need for holistic care of breathlessness. University of Bristol. Available <http://www.bristol.ac.uk/policybristol/policy-briefings/life-of-breath/> (Accessed 05/10/2022)
7. Lewis A, Cave P, Stern M, et al. (2018). Singing for Lung Health-a systematic review of the literature and consensus statement. NPJ Prim Care Respir Med.
8. Natural England Commissioned Reports, Number204. Available from <http://publications.naturalengland.org.uk/publication/4513819616346112> (Accessed 05/10/2022)
9. Li, Q (2019) Into the Forest: How trees can help you find health and happiness. Penguin.