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**Title:** Looking after your lungs: improving the respiratory health of adults with learning disabilities

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**Key words:**

**Abstract** (75-100/120-150)

People with learning disabilities are up to five times more likely to die from respiratory tract disease and infections than people without learning disabilities. Learning disability services

support many people with compromised or vulnerable respiratory status. This paper describes a lung health group developed by physiotherapists and speech and language therapists. The group aimed to: improve respiratory health of people with vulnerable respiratory status, particularly over the period of greatest risk of airborne respiratory infections; reduce the number and/or severity of chest infections and improve carer knowledge of respiratory health. The paper describes the group content and format, methods trialled to evaluate the group, and benefits from attending the group.

**Introduction**

Respiratory illness is the most common immediate cause of death amongst people with learning disabilities in England; twice as many people with learning disabilities die from a respiratory illness than people without learning disabilities and lung problems caused by aspiration are an important preventable common cause of death (Glover and Ayub, 2010). The Confidential Inquiry into the Premature Deaths in People with Learning Disabilities recommended that adults with learning disabilities be considered a high-risk group for deaths from respiratory problems (Heslop et al., 2013).

Many individuals supported by learning disability services will have compromised or vulnerable respiratory status. Risk of respiratory issues is significantly increased in: people with physical impairments who may be immobile or have postural issues affecting lung volume (Marks and Rainbow, 2001); people with aspiration due to dysphagia; or people with severe gastro-oesophageal reflux leading to acute, chronic or recurrent respiratory symptoms (Hibberd et al.,

2013). Dysphagia is a significant health risk for people with learning disabilities (NPSA, 2004) and 40% of people with learning disabilities and dysphagia experience recurrent chest infections (Chadwick and Jolliffe, 2009). Furthermore, people with respiratory problems often have shallower or irregular breathing patterns which may affect safe swallowing co-ordination and increase aspiration risk (Logemann, 1998; Martin et al., 1994; Wright D et al., 2014), leading to a potential cycle of respiratory risk.

Physiotherapy and speech and language therapy (SLT) teams within Manchester's community adult learning disability teams/service were concerned about the vulnerable respiratory status of many people known to services. The physiotherapy team work with people with complex physical disabilities including wheelchair users and people with postural issues, whilst the speech and language therapy team support many people with dysphagia; many of whom contract more respiratory tract infections over autumn/winter. Existing local groups for people with poor respiratory health are often inaccessible to people with learning disabilities due to:

- Cognitive and physical skills required to take part
- Inclusion criteria for the group/intervention: most people with learning disabilities have a collection of risk factors rather than a single underlying lung condition
- Differing aetiology (e.g. more people with learning disabilities have dysphagia than the wider population)

Therefore, it was decided to develop a lung health group specifically for people with learning disabilities. The group's central aims were to:

- Improve lung health of people with vulnerable respiratory status, particularly over the period of greatest risk of airborne respiratory infections.
- Reduce number and/or severity of chest infections contracted by people with poor underlying respiratory health.
- Give people tools to improve their lung health (e.g. sputum clearance techniques).
- Improve carer knowledge of the importance of respiratory health and how this may be improved.

Additional potential benefits of improving respiratory health are increased life expectancy, reductions in related problems (e.g. secondary chest complications and malnutrition), improved psychological wellbeing and quality of life and reduced use of antibiotics and healthcare (RCSLT, 2015). A group format was chosen as more people would receive the intervention and social interaction was an important component of the exercises and learning. The group was aimed at individuals with the cognitive ability to understand and follow simple instructions or to copy actions.

Carer involvement was crucial to increase awareness of risks and risk management, to share this knowledge with support teams, support generalisation of strategies beyond the group, and facilitate physiotherapy and speech and language therapy referrals where more specialised input was required.

**Lung group content and format**

Physiotherapy and SLT teams invited people with respiratory issues due to the risk factors described to attend eleven sessions between December 2015–March 2016. Seven people gave

informed consent to participation whilst a best interests decision was needed for one group member to attend. During the planning stage the people with learning disabilities we spoke to about the group started calling it 'the lung group', therefore this was the final choice of name. Each one-hour session was facilitated by physiotherapy and SLT staff.

An adapted version of the active cycle of breathing technique (ACBT) formed the basis for the lung group sessions. This is a long-established breathing technique typically taught by physiotherapists to patients with a variety of respiratory conditions that helps to loosen and clear sputum from the lungs, improve lung ventilation, and improve cough efficiency (Bott et al., 2009). The cycle is made up of three main types of breathing: deep breathing, forced expiratory effort and relaxed breathing (Box 1).

**Box 1: Active Breathing Cycle**

**Deep breathing** – slightly raising the heart rate (e.g. by gentle exercises involving raising arms above the head) encourages the body to breathe more deeply, helping to get air into the base of the lungs.

**Forced expiratory effort** –aims to move air more rapidly around the lungs to move phlegm that has built up in the lung bases, a common problem for people who cannot participate regularly in vigorous exercise.

**Relaxed breathing** – overdoing the deep breathing and forced expiratory effort parts of the cycle may make someone breathless and dizzy. Therefore, the cycle incorporates short periods of completely relaxed breathing, concentrating on slowly breathing in and

out.

ACBT usually requires participants to understand the process and purpose of each stage and carry out an exercise program independently. This would be difficult for the people the group was aimed at; however, it was felt that ACBT could be adapted to meet their needs. Integral to this was incorporating games and exercises to engage group participants through the different phases of the cycle (Box 2). Passing a beach ball around the group and seated tai chi movements encouraged deep breathing. Single-user cleanable or disposable blowing instruments and singing facilitated forced expiratory effort. During relaxed breathing, participants rested rubber ducks or sensory materials on their stomachs to help to see the breathing movement.

**Box 2: Lung group session plan**

**Lung Group Session Plan : ongoing sessions**

- Introductions and housekeeping – toilets, fire exits
- Why are we here? (without mention of exercise!)
- Warm up dancing to music – neck, arm & finger stretches
- Singing: Happy Birthday if applicable to someone in the group/group members' choice
- Mexican wave – leading into first active breathing cycle

| Activity (+ time) | Aim | Resources |
|---|---|---|
| Tai chi movements | Deep breathing | Arms (!) and music |
| Duck | Relaxed breathing (tummy breathing) | Ducks<br>Relaxing music |
| Tai chi movements | Deep breathing | Steady music |
| Blowing feathers/ tissue paper/ shiny fringing | Forced expiratory effort | Multi-coloured feathers/tissue paper |
| | | |
| Beach ball – pass round x 2 or balloon-bashing | Deep breathing | Beach ball & music<br>or balloons + music |
| Duck | Relaxed breathing | Ducks<br>Relaxing music |
| Beach ball – pass round x 2 | Deep breathing | Ball |
| Blowing recorders/ shouting/ give choice of activity according to individual ability/ preference | Forced expiratory effort | Mini recorders/ range of objects encouraging forced expiration |
| | | |
| Relaxation time<br>- Lights off (with small colour-changing focus?)<br>- Guided imagery<br>- Relaxing music | Relaxed breathing | Duck – hold to diaphragm |

Group participants did not have a common health condition and varied in physical mobility and the level to which they could form a lip seal and forcibly expel air making it important that components of the cycle could be individualised. For example, for forced expiratory effort, participants with good lip seal could use party blowers, recorders or kazoos; those without good lip seal were offered alternatives to provide positive visual feedback (e.g. tissue butterflies, tinsel fringe/pompoms, feathers). Hands-on postural support was provided where people had difficulties carrying out movements due to posture or muscle tone.

Participants could take the instruments home to practise between sessions. Often individual issues were discussed with participants and carers at the end of sessions.

**Evaluation methods**

To evaluate the impact of the group on respiratory health quantitative information was collected on:

- Respiratory infection rates: GPs were contacted to provide information about number of chest infections and hospital admissions between 2014-16.
- Oxygen saturation and heart rate at the beginning and end of each session (measured using a pulsoximeter).

Additional qualitative measures included:

- Clinical notes recorded observations about respiratory function during each session.
- Each week participants and carers were asked to rate the participants' chest health since the last session.
- Participants and carers completed questionnaires at the final session rating different aspects of the group, perceived benefits for participants with learning disabilities (respiratory, social and knowledge) and change in lung health knowledge. Open questions were included to gather qualitative feedback.

**Findings**

Four men and four women with learning disabilities attended between three and ten sessions: two people attended three sessions; the remainder came to five or more sessions. Reasons for

non-attendance were: other commitments, inadequate staffing, health appointments, being unwell and transport. The mean age was 55.75 years (range=24-75, SD=16.4). Six people were White British, one was Asian/Asian British/Pakistani, one was Middle Eastern. Six people used a wheelchair. Six people lived in supported housing and two lived with family. One person was supported at the group by her mother, the others by support workers.

Participants showed improved respiratory skills in relation to lip seal, force of expiration and/or breath control (Box 3), as captured through detailed clinical observation. The majority of participants engaged with and appeared to enjoy the group and there were improvements in quality of life as skills were used beyond the group (e.g. Bob having party blowers on his birthday for the first time).

**Box 3:**

**Bob** is a 66-year-old wheelchair-user living in supported housing. He has problems with sputum retention and a weak cough and has been hospitalised several times due to chest infections. At the first session he could not form a lip seal so could not use the recorder, party blower or kazoo; by the end of the group he could use the party blower and recorder. Bob was able to use party blowers at his birthday party for the first time and his support staff bought him a recorder as a present which he continues to play at home. Bob was a particularly enthusiastic singer!

**Reema** is 24 years old and lives at home with her family. She uses a wheelchair and wears a chest brace because of scoliosis. Her mother supported her at the group. Reema has difficulty in group settings because she has impaired hearing making it more difficult to follow instructions and participate in group discussions. Her mother translated for her using sign and visual cues such as the glowing star used during the relaxation session were also important. Her chest brace impacted on how well she could feel her chest expanding or stomach moving during the breathing exercises and she has limited arm movements but she joined in the breathing and movement exercises. She practised with a party blower at home and in the car. Initially Reema had no lip seal and could not blow any of the items. By the final session she could make a lip seal, use a recorder (demonstrating more breath control) and make a noise using a party blower (demonstrating more force). The timing of the group was not ideal for her so it was positive that they attended so

| | |
|---|---|
| many sessions.<br><br>**Charles** is 63 years old and lives in supported living. He uses a wheelchair and has severe kyphosis which can lead to problems breathing and eating. He is visually impaired and seemed very engaged with the group. He could use the kazoo from the first session and used this throughout. With verbal direction he could blow for longer time periods and vary volume demonstrating improved breath control and expiratory force. His chest expansion improved when his posture was facilitated by physiotherapy or support staff and he continued to need facilitation for optimum posture. He missed the first session because of a chest infection but had no further infections during the course. He was an enthusiastic singer and said he enjoyed the group.<br><br>**Jennifer** is a 67 year-old woman who uses a wheelchair and lives in supported housing. She is percutaneous endoscopic gastrostomy (PEG) fed. Initially she was unable to achieve any force during expiration and struggled to control any aspect of her breathing for exercises. After a few sessions there were some small improvements controlling expiration and she made the feathers and butterflies move and made some noise using the kazoo. She seemed very proud of her improvements and engaged more in the group as she improved. By the end of the course she could make more noise using the recorder and the kazoo. She needed facilitation for all of her upper limb movements but there was less resistance in her movements by the end of the group. She missed the first two sessions due to a chest infection but had no further chest infections during the time period of the group.<br><br>**Clarissa** is 75 years old, has COPD, has had a stroke and requires dysphagia management. She had two chest infections in 2015 and one in 2016. She has reduced mobility, using a wheelchair when she goes out. She had good forced expiration and breath control from the outset of the group and as a former smoker who uses an e-cigarette had a good lip seal although she tended to breathe in rather than out. She took the party blower home and used them. She seemed to enjoy the forced expiration and beach ball exercises but did not like any of the activities that were referred to as 'exercise', or the relaxation as she felt that she could do this at home. She came to three groups after which she told her support worker, "I know everything there is to know about lungs. I don't need to go any more." | |

Five people with learning disabilities completed questionnaires. All were satisfied with most aspects of the group (fun, meeting people, relaxation, warm-up, stretching, blowing exercises).

Two participants were neutral about the singing, relaxed breathing and venue. There were no negative responses.

Feedback from the five carers who completed questionnaires was generally positive. Every carer felt the person they supported benefited from the group and they strongly agreed/agreed with statements that the group was successful, fun and tailored to meet people's needs, that appropriate methods and materials were used, and that the person they support benefited. Only one respondent was unsure about whether the group enabled the person to see friends/make new friends. Four out of five carers strongly agreed/agreed that the group helped the person or carer learn about lung health and there was some ambiguity about whether the group had improved the person's cough or phlegm (Figure 1). Comments suggested that social aspects of the group and engagement in the group were particularly valued (Box 4). Four people practised lung group exercises at home.

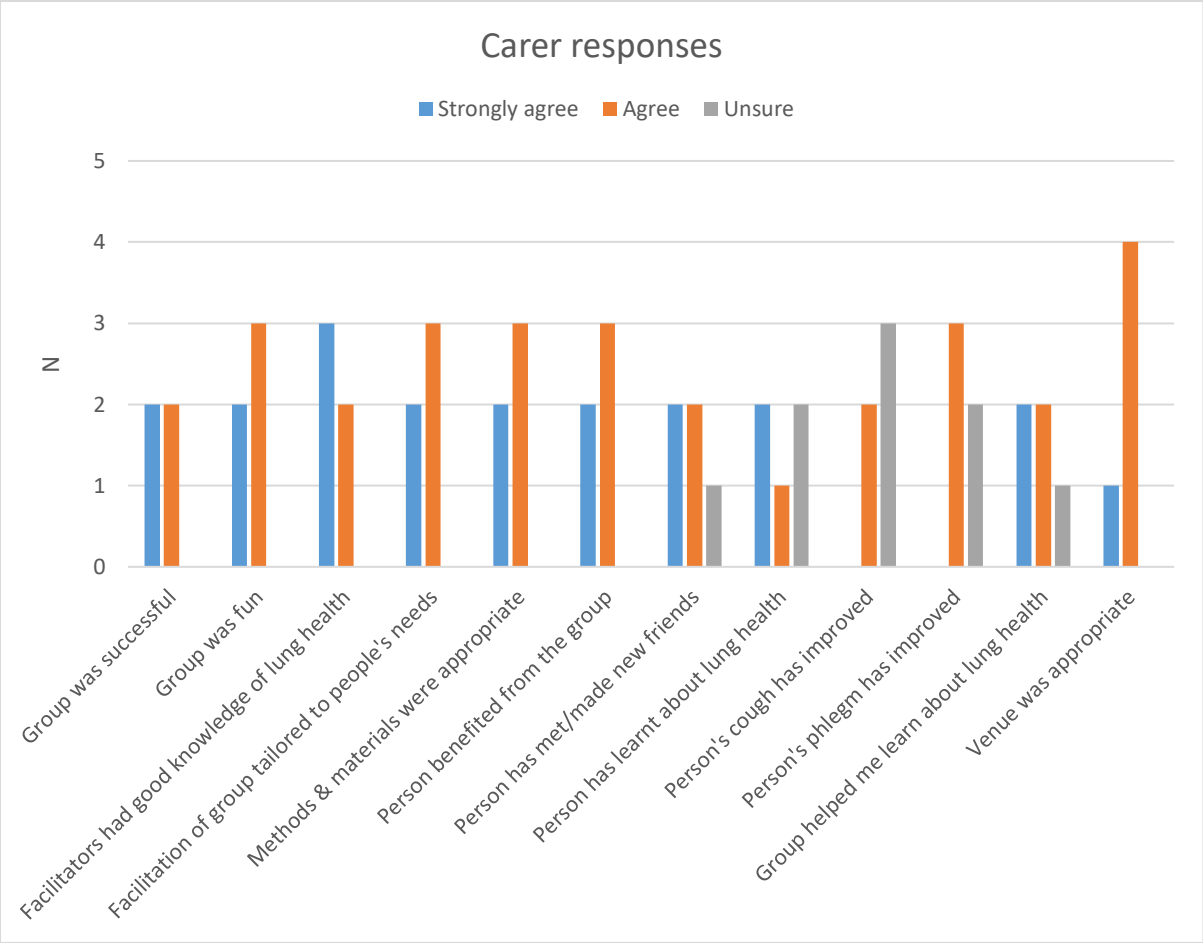
Carers who attended consistently showed more confidence supporting people to do exercises as the course progressed and were more likely to support the person to participate in the group and practise exercises between sessions.

Chest infection data was inconclusive as only three GPs provided information which was not always clear or comparable. Three people missed initial sessions due to chest infections; however, no-one was reported to have had a chest infection whilst attending the group.

Oxygen saturation measures were taken at the beginning and end of each session. However, the data was not considered accurate enough to enable meaningful analysis. It was not always

possible to take pre and post measures if someone arrived late or left early, and high initial O2 levels led to a ceiling effect.

**Figure 1: Carer feedback on the group**




**Box 4: Comments about the group**

"It was good for him to socialise with everyone."
"The social side plus the participation and health values."
"I enjoyed it. Wish there was more sessions."
"Room could do with a good clean. Found the warm up hard sometimes. Found the stretching hard sometimes. Found the blowing exercises hard some days but got there."

**Discussion**

Whilst it was difficult to collect objective outcome measures, these initial findings are positive suggesting that a lung group adapted for adults with learning disabilities can improve respiratory skills and be positively experienced by participants. There are a number of implications for future service delivery, research and evaluation.

The group could be delivered slightly differently with potentially more impact. Shorter courses held in more locations would reach more people. As the group content, materials and process have been developed and physiotherapists and SLTs now have the necessary knowledge and skills, two people could facilitate the course; one from each profession, to ensure all aspects are covered.

This project demonstrates the value of multidisciplinary working; this was important to plan and deliver the group and has improved the skill set of all professionals involved. SLT developed accessible resources and identified people with dysphagia/respiratory risk factors who might benefit from the group. Physiotherapy knowledge of ACBT was central to the group's development, they identified people with postural and respiratory issues who might benefit. As registered movers and handlers, physiotherapy staff facilitated people with restricted range of movement and poor muscle tone to carry out exercises and maximise posture and chest expansion during sessions. Long term involvement of both SLT and physiotherapy would be beneficial in order to incorporate the expertise of both disciplines (RCSLT, 2015). Physiotherapists are well placed to facilitate ACBT groups including any physical support required; SLTs ensure that the groups are accessible and advise on cough and dysphagia management. Qualified therapists from each profession need to be available throughout the group should problems or queries arise. Ideally initial assessment prior to the

group will ascertain whether the physical exercises are possible for participants and whether there are other relevant risk factors present.

People with more profound and complex cognitive disabilities were not invited to the group as participants needed to understand or copy directions. Alternative ways of improving their respiratory health were considered such as individual physiotherapy input and postural management for people who need physical manual handling to achieve respiratory stimulation and speech and language therapy intervention in dysphagia management to manage aspiration-related respiratory issues.

Evaluating the lung group was challenging with difficulties collecting quantitative outcome measures. Standardised objective measures of respiratory function (e.g. peak flow, 6-minute walk test) were inappropriate for most participants due to walking ability or respiratory and cognitive skills to use a spirometer. Existing lung function questionnaires are inaccessible to people with learning disabilities due to language used, length, response systems and activities referred to (e.g. Breathlessness, Cough, and Sputum Scale, St. George's Respiratory Questionnaire). Chest infection data were inconclusive, further compounded by the low response rate and oxygen saturation measures did not give any meaningful data. Detailed clinical observation notes were valuable to reflect subtle changes, particularly given the challenges gathering objective measurements.

Alternative methods of objectively measuring respiratory health may be needed for people with learning disabilities. Future evaluations need to look again as to whether there are any reliable measurements which could be gathered over a longer time period, not necessarily

during sessions. As changes in lung function take time to achieve, a measure of respiratory health before and after the lung group intervention may be more meaningful than collecting data at each session. Long term changes in lung function and whether people continue to practice the adapted ACBT exercises need to be examined.

**Conclusion**

It is possible to teach ACBT to people with learning disabilities and carers in a group setting and this appears to improve respiratory skills, carer knowledge and be enjoyed by participants. There is little research on how to improve the respiratory health of people with learning disabilities, despite this being a leading cause of death and there is a need for more rigorous outcome measures and evaluation methods to develop the evidence base.

**Implications for practice**

- Existing lung health groups are often inaccessible for people with learning disabilities
- Providing a lung health group based on the Active Cycle of Breathing Technique can lead to improvements in respiratory skills
- It is important to actively involve carers to increase their knowledge of the importance of respiratory health and exercises that may improve respiratory health
- It is important to consider ways of improving the lung health of people with more severe learning disabilities

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